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ABSTRACT

This issue of Zero to Three, the bulletin of the National Center for Clinical Infant Programs, focuses on changes occurring in neonatal intensive care to provide greater developmental nurturance to newborns and their parents. Articles include: (1) "Developmentally Supportive Care in the Neonatal Intensive Care Unit" (Heidelise Als and Linda Gilkerson); (2) "Newborn Intensive Care Units Pioneer Family-Centered Change in Hospitals across the Country" (Beverley H. Johnson); (3) "The Colorado Consortium of Intensive Care Nurseries: Spinning a Web of Support for Colorado Infants and Families" (Joy V. Browne and Suzanne Smith-Sharp); (4) "Nursing the Premature Infant" (Lydia Furman); and (5) "Early Intervention and the NICU Health Professional: An Interdisciplinary Training Model" (Virginia Wyly and Jack Allen). The issue also includes letters to the editor, reviews of publications and videos, descriptions of upcoming conferences, and a topic index of 1995 issues. (JW)

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Department of Photography, Denver Children's Hospital

Developmentally Supportive Care in the Neonatal Intensive Care Unit

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Over the past 15 years, neonatal intensive care units have been involved in a transformation of care which has been described as the most profound change that has occurred in neonatal nursing practice (Gilkerson & Als, 1995). These nurseries are moving toward a new model of family-centered, developmentally supportive care—a professional and family alliance which supports the parent's engrossment with their child and the child's neurobiologically-based expectations for nurturance (Als, 1993).

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Editor's Note

The contributors to this issue of *Zero to Three* are pioneers in a movement to help intensive care nurseries become not only technically proficient mechanisms for saving the lives of preterm and critically ill infants but also supportive, nurturing environments which enhance the development of all involved—the infant, the family, and the staff.

Joy Browne and Suzanne Smith-Sharp's image of a "web of support," which they use in relation to the Colorado Consortium of intensive care nurseries, aptly describes many efforts to provide developmentally supportive and family-centered care in the NICU and beyond. Heidelise Als and Linda Gilkerson, for example, explore "the responsibility of connectedness" as rewarding, but difficult, in the intensivist, interdependent NICU environment. Beverley Johnson describes a "web" of family-centered care, promoting practices that nurture the strong bonds that begin between infants and their families before birth and supporting those relationships throughout the intensive care experience. Describing the challenge of nursing a premature infant, Lydia Furman notes that "nursing is a relationship, and its support may best be accomplished via a relationship"—possibly from a nursing "doula." Virginia Wyly and Jack Allen recognize the challenge of providing family-centered early intervention services in the NICU, through discharge, and in transition to community early intervention services—and their integrated training of NICU health professionals and early interventionists is helping to make this happen.

An especially skillful web-spinner is Margie Wagner, who describes no less than 19 videotapes, for parents and professional audiences, about the care of premature and high-risk infants, in the NICU and after discharge.

Emily Fenichel, Editor

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Developmentally Supportive Care in the Neonatal Intensive Care Unit

continued from page 1

Brain development in the full-term infant occurs in the intrauterine environment, an environment mediated by maternal protection from environmental perturbations, with an ongoing supply of nutrients, continuous temperature control, and regulating chronobiological rhythms. In contrast, premature infants are cared for in the NICU at the time when their brains are growing more rapidly than any other period in their life (McLennan, Gilles, & Neff, 1983). The preterm infant's nervous system is being shaped in a setting characterized by sensory overload and, therefore, by a stark sensory mismatch to the developing nervous system's expectation for environmental inputs (Als et al, 1979; Freud, 1991; Gottfried & Gaiter, 1985; Wolke, 1987). From an evolutionary perspective as members of the human species, preterm infants are neurobiologically social (Als, 1977; Als et al, 1979; Als & Duffy, 1982) and expect the security of three inherited environments to support their development: their mother's womb, their parents' bodies, and their family's social group (Hofer, 1987). Thus, safeguarding the parent's role as the infant's primary nurturers is fundamental to the survival and growth of the premature infant (Als, 1992; Als, in press). How does one estimate the potential effects on the infant's nervous system of moving too early from the relative equilibrium of the intrauterine aquatic econiche of the mother, to the extrauterine terrestrial environment of the NICU (Alberts & Cramer, 1988) by-passing the on-parent body phase of early nurturance? What impact does this disruption have on the infant's and family's development? How can the life-saving intensive care nursery become a supportive, nurturing environment that enhances the development of all involved?

Developmentally supportive care

The developmental approach views the infant as an active collaborator in his own care, determinedly striving to continue his developmental trajectory (Als, in press). This approach postulates that the infant's behavior provides the best information base from which to design care (Als, 1982). Collaborating with the infant, then, involves inferring from the infant's own behavior what he seeks to accomplish and what strategies he is using, and estimating what supports might be useful to facilitate the infant's overall development and neurobehavioral organization in the face of necessary medical and nursing interventions. The questions become: What is the infant's developmental agenda? (Als, 1978) and How can caregiving be implemented in a way that respects and furthers the infant's development while at the same time accomplishes the caregiving goals?

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) model was developed as a framework for the implementation of developmental care (Als & Gibes, 1986). The NIDCAP approach includes a systematic method for the detailed observation of infant behavior and for the use of each infant's unique repertoire of strategies as a guide for caregiving. Typically, a developmentally trained professional works in partnership with a developmentally trained nurse to support the primary care team and the family. The developmental professionals conduct the observations, prepare detailed reports with suggestions for ways to support the infant's physiological stability, behavioral organization, and developmental progression, and share this information with the caregiving teams and the family.

Behavioral observation

The detailed behavioral observation documents the language of the infant's behavior in three channels of communication: the autonomic system, motor system, and the state system (Als, 1982). As described elsewhere (Als, in press), the autonomic nervous system's functioning can be observed in the infant's breathing patterns, color fluctuation, visceral stability or instability, and autonomic behaviors such as tremors and startles. Is this an infant who breathes smoothly and regularly? Or does he quickly show, even when challenged with only the slightest touch, movement, or sound, irregular respiration, pauses or tachypneic bursts? Is this an infant who maintains his color well throughout face and body or does he quickly become pale, and cyanotic? Does this infant maintain a steady visceral system even when interacted with vigorously or does he quickly begin to hiccough, gag, spit up, or defecate in response to mild input?

Simultaneously, motor system functioning can be observed in the infant's body tone, postural repertoire and movement patterns. Does the infant maintain tone well, showing animated facial expression and well-toned limbs throughout? Or does he quickly become flaccid, lose tone in the face, trunk, and extremities? When still, does the infant maintain soft flexion or does he quickly become overly flexed, appearing to use hyperflexion for self-protection? Or, the opposite, does the infant overly extend arms, legs, fingers, and toes in full extension, face retracted, head, neck, and back arched and extended? When the infant moves, are the movements smooth and well controlled or are they quickly disorganized, with poor flexor/extensor balance?

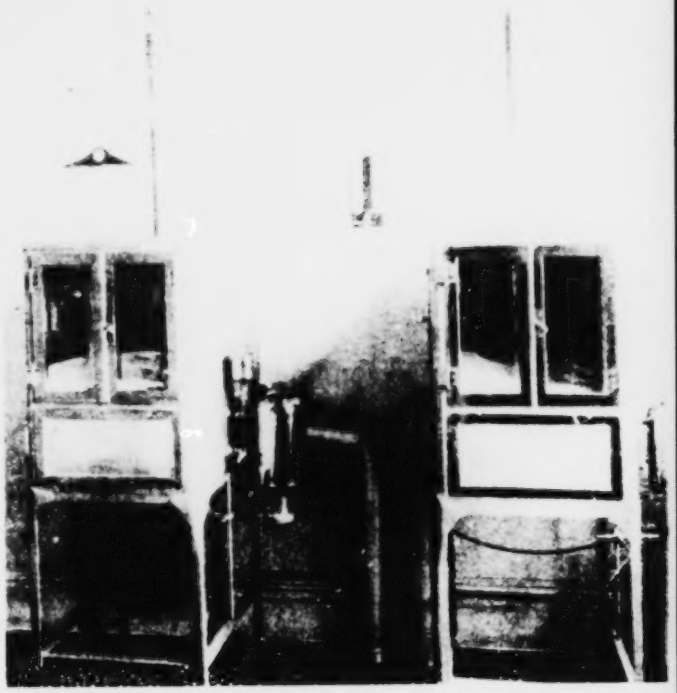
The infant's state organization (Brazelton, 1984) can be observed in terms of the infant's range of states, the robustness and modulation of the available states, and the patterns of transition from state to state. Is this an

infant who shows the full continuum of states moving from deep sleep to light sleep, to a drowsy state, to quiet alertness, to an active aroused state to upset and crying behavior? Or does the infant typically move from sleep to aroused states and immediately back down to sleep again, skipping the alert state? When the infant is sleeping, is the sleep robust, or does the infant never quite settle, showing facial movements, vocal discharges, and general restlessness? What is the quality of the infant's alert state? Is his expression animated, with shiny-eyed alertness and gently forward-shaped mouth, available for engagement and interaction? Does the infant quickly move to panicked, wide-eyedness or does he barely seem to muster the energy to interact through lidded, glassy-eyed, strained appearance?

The observations may be conducted weekly or as clinically deemed necessary by a developmental specialist and take place at a mutually agreed upon time when the nurse or other caregiver is interacting with the infant (e.g., taking vital signs, diapering, or suctioning). The observer does not interact with the infant, but stands close by watching and recording at two-minute intervals on a NIDCAP check sheet. In order to arrive at a sufficient sample of behavior, the infant is observed for at least 20 minutes before interaction with the caregiver, throughout the caregiver interaction, and for 20 minutes after. In addition to recording the details of behavior, the observer notes physiologic data (e.g., heart rate, respiration rate, and oxygenation), light and sound levels, and environmental activity around the bedside. Caregiving interactions are also described.

Behavioral interpretation

All observations are seen in the context of the infant's efforts at self-regulation through approach and avoidance behaviors (Als, in press). This framework assumes that the infant has strategies available to move toward and take in stimuli, if the input is appropriate in timing, complexity, and intensity in relation to the infant's thresholds of functioning and, conversely, that the infant has strategies to move away from or avoid inputs which are too complex or intense or are inappropriately timed. Such behaviors are thought of as stress behaviors. Of course approach and self-regulatory behaviors can shift and become stress behaviors; the same behaviors, when successful in reducing stress, can serve as self-regulatory strategies. For example, for the very young infant, a hand on the face and mouthing may represent stability, yet if overly frequent, these behaviors may indicate stress, or possibly seizure activity. As a general rule, extension behaviors are thought to reflect stress, and flexion behaviors are thought to reflect self-regulatory competence. Diffuse behaviors are thought to reflect stress, and well-defined behaviors are thought to reflect regulatory balance. Self-regulatory balance is reflected by the presence of regular respirations, pink color, a stable visceral system, smooth movements,



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Full length view of two incubators at the Chicago Lying-In Hospital, circa 1901.

modulated tone and softly flexed posture, and steady sleep and awake states.

The developmental professional prepares a descriptive narrative based on the observed behavioral dialogue between the infant and the caregiver. The narrative begins with a description of the environment surrounding the bedspace. Next, the behavioral picture of the infant before active caregiving is described in relationship to physiological measures. Then the caregiving interaction with detailed focus on the infant is documented, including the infant's efforts, initiations, and responses as well as the caregiver's efforts to aid the infant. Repeated observations reveal much information about the infant's strengths and robustness and the goodness-of-fit between the infant and the care provided. The infant's behavior is interpreted as to the infant's apparent current developmental goals. The narrative concludes with caregiving suggestions and environmental modifications to consider in order to more finely attune care to the infant's behavioral thresholds and to support the infant's developmental trajectory. The narrative is shared with the infant's professional caregivers and with the family, and, depending on the nursery's stage in developmental care integration, included in the infant's medical chart (Als et al, 1986; Als et al, 1994).

NIDCAP guidelines for care

In order to effectively implement developmentally supportive care within the NIDCAP framework, Holmes, Sheldon, & Als (in preparation) and Vento & Fineberg (in press) have outlined guidelines for care. Following is a description of a developmental care environment based on their recommendations.

• **Consistency of caregiving:** Within 24 hours after admission, a primary team is identified for each infant. The team includes the family and specific representatives from medicine, nursing, respiratory therapy, and social work as well as a specially trained developmental professional. The team works collaboratively with the family to develop an individualized plan of care which should be reviewed daily on rounds and discussed in regularly scheduled team meetings with the family.

• **Structuring the infant's 24-hour day:** In order to provide the infant with sufficient rest and to support growth, interventions are organized into individually appropriate clusters timed in accordance with the infant's sleep-wake cycles, states of alertness, medical needs, and feeding competence. All caregiving interactions are evaluated regarding their necessity and appropriateness, e.g., does an infant in need of ventilation have to be suctioned on a fixed schedule or as clinically indicated? Taxing procedures such as suctioning are performed by two-person teams.

• **Pacing of caregiving:** During the delivery of care, caregivers approach the infant and family in a calm manner, explaining to the family the goal and sequence of care. The care provider organizes the environment, gathers needed materials, and prepares herself to be attentionally and emotionally available to the infant and family. The infant is observed before hands-on interaction. The caregiver then introduces herself to the infant with a soft voice and gentle containing touch. During care, the infant is offered periods of rest and recovery between caregiving actions and containment through gentle holding or handswaddling, finger-holding, or sucking on a pacifier or finger. Parents are nurtured in supporting their infant during caregiving as the infant needs the comfort and security of this family's care. Since the infant comes to recognize the familiarity of the parents' hands, bodies, and voices, he is comforted by their presence and often shows increased physiologic stability when they are present. The care provider stays with the infant and family by the bedside after care to assure that the infant is settling comfortably.

• **Support during transitions:** Increased support is typically needed around transitions, particularly between caregiving activities (e.g., ventilator care, position changes, feeding, diapering) and around the beginnings and endings of care. Extra support is needed as the infant awakens or when the infant makes efforts to sleep. Caregiver interactions are guided by the infant's behavioral cues with special attention given to the facilitation of restful sleep at the end of the alert state.

• **Appropriate positioning:** Infants are supported into softly flexed, comfortable aligned positions during sleep, feeding, bathing, and necessary procedures. Positioning can be supported with aids such as blanket rolls, nesting, gentle swaddling, special buntings, and hands-on containment. Sidelying or prone positioning, if the infant has sufficient strength, is typically more desirable that supine positioning for comfort and for physiological stability. Supports are used in an effort to enhance the infant's own competence and gradually decreased as the infant's autonomous regulation increases.

• **Individualized feeding support:** Feeding method and schedule are determined by the infant's individual needs and competencies. Feeding should be a pleasurable experience for the infant, one over which the infant takes increased initiation and control. Caregivers hold the infant in a secure and comfortable position. Often semi-upright with soft flexion cradled in the caregiver's arms is quite supportive. Attention to the infant's autonomic, motor, and state systems guide the pace of the feeding.

• **Opportunities for skin-to-skin holding:** Opportunities for mothers and fathers to hold their infants, including ventilated infants, skin-to-skin (Kangaroo Care) are available at all times. Infants have been found to experience increased respiratory stability and more restful sleep when held by the parents, while parents report that they experience a sense of calm and fulfillment. Staff receive support and education so that they are comfortable facilitating skin-to-skin holding and providing caregiving while the infant is being held by the parents.

• **Collaborative care:** All special examination and assessment procedures, including physical exams, ultrasounds, chest films, and neurology examinations are performed collaboratively by the respective specialist assisted by the infant's nurse and, if possible, facilitated by the parent to support the infant's comfort and well-being. This allows infants to be cared for during procedures by persons who know them and how they respond to stress and to comforting.

• **Quiet, soothing environment:** Nurseries should be quiet, soothing places where thoughtful consideration is given to the lighting, sound, and physical arrangement. The lighting plan should include individualized bedside lighting with dimmer capacity and indirect, readily adjustable general lighting. A variety of sound containing procedures are used, including separate spaces away from the infant's beds for admissions and rounds, elimination of radios and overhead pagers, and sound dampening strategies for commonly used equipment (e.g., vibrating rather than sound beepers, sound shielding blankets for incubator covers, and a flashing light which is triggered when the sound rises above agreed upon levels).

• **Family comfort:** A useful way to sensitize staff to the messages conveyed to parents by the environment is for

staff to walk the path from the hospital's parking lot to the infant's bedside (Als, in press). What does the layout say to parents about the importance of their role in their child's care? Parents are exquisitely attuned to the emotional ambiance of the setting. What is conveyed by the behavior of those with whom the family comes into contact with, from the parking lot attendant to the attending physician? To increase family comfort in the unit it is recommended that home-like, individualized spaces for families be provided. Recliner chairs big enough for two persons are available at each bedside. Parents should be encouraged to view the space around their infant's bedside as theirs, to be arranged to their liking; to bring clothing, blankets, toys, pictures and other items from home to personalize their infant's bedspace. Twins are cared for by the same team together in the same area, if not in the same incubator or crib. Readily available, trained, child care support is provided for siblings.

• **Developmental support:** Specially trained developmental professionals should be on staff full-time. These professionals should be knowledgeable about infant and family development, support the primary care teams, and serve as resources and catalysts in the implementation of developmental care. Developmental professionals should be linked with their counterparts in other units and have opportunities to participate in relevant local, regional, and national conferences. Nursery-wide implementation should be supported by a multi-disciplinary developmental team. The team should have access to unit-specific training and consultation opportunities, including an opportunity to develop a process for monitoring and reflecting upon the process of change (Gilkerson & Als, 1995). A Parent Council with multicultural representation should also be formed. Families and staff should have ready access to psychosocial support. Formal arrangements to use the expertise of a licensed clinical social worker, psychiatric nurse, or psychology/psychiatry consultant should be in place.

Fundamental principles of infant caregiving

While developmental practices may at first glance seem foreign within the context of newborn intensive care, they are based on fundamental principles of infant caregiving that transcend settings. Winnicott is quoted with saying: "A baby is always contending with being done to." Regardless of the setting, three features should characterize infant caregiving: individualization, responsiveness, and respectfulness (Gerber, 1979). Gonzalez-Mena & Eyer (1980) offer 10 principles of relating to an infant with respect. Among these are: involve infants in things that concern them, invest in time when you are totally available, learn the infants' unique ways of communicating and give them the opportunity to experience yours, respect infants as individuals, build security by teaching trust, and be concerned about the quality of development in each stage (p. 9-10).

Developmental care ensures that infants are thought about individually in the NICU environment, and conceived of as competent to collaborate in their own care. The developmental approach asks NICU caregivers to watch closely for the infant's own efforts, to notice in what context the infant is most well-regulated and competent, and to offer just enough assistance to support the infant's own developing capacities and next steps. The guidelines for feeding stress the importance of the infant's increasing initiative and competence. In this way, caregivers promote the development of effectance, effectance motivation, and the experiences of mastery outside of the womb.

In the day care literature, considerable attention is paid to the activities of physical caregiving: diapering, feeding, sleeping, comforting. Caregiving is defined as not just the activity, but the entire sequence and ambiance of care: what happens before, during, and after. This approach is illustrated in the following description of diapering in an infant care program:

> *First prepare the environment and get the materials ready. Next go to the child, but first, let her be. Watch and wait until she notices you. Let her know what will happen and tell her about each step along the way. After care, stay with her until she has settled with an activity and is re-engaged* (Abel, personal communication, 1995).

The developmental approach brings this same attention to the process of caregiving to the NICU. Because infants are forming their perceptions of the world, they absorb not only what is done in physical caregiving, but the manner in which it is done. Gonzalez-Mena and Eyer (1980) point out that certain basic needs of the infant are met through physical care; other higher level needs are met in the way the physical care is delivered. The pacing of care, so central to the developmental approach, allows for a thoughtful, unhurried, finely attuned dialogue between infant and caregiver. This kind of early experience communicates to the infant important messages about the human environment.

Lally and Phelps (1994) stress that settings for infants should offer security, protection, and intimacy. Primary caregiving arrangements and continuity of providers are central to creating a sense of security and trust for the infant and for the family. When caregivers are continually changing, infants have to work harder to get their message across (Lally & Phelps, 1994); but also have no opportunity to develop expectancies and therewith trust. This has been shown to lead to depression, failure to thrive, and hospitalism syndromes. For infants who are premature and medically fragile, this is of even greater seriousness since the resources to rally in the face of stress are more limited.

The presence of parents is the most fundamental basic security that an infant can have; it is imperative

that staff be supported and educated about the primacy of parenting and about their role in supporting the realignment of parental and fetal infant co-regulatory energies. The professional caregiver's own direct interaction with an infant in the NICU needs to model the attunement to the personhood of that infant at all times. This assures the parent of the appropriateness of the affective value with which they imbue each of the child's movements and actions, no matter how small. This co-regulatory nurturance of attunement through modeling and through respectful preparation of appropriate settingss for the parent/infant co-regulation is the professional caregiver's most far reaching responsibility in the service of the infant's well-being. This is of particular importance because of the very intensivist setting which the infant requires. The developmental model not only seeks to protect the infant from inappropriate and oversfimulation and from unnecessary procedures but seeks to assure that each infant is cared for by persons who know the infant intimately, that is, who know the infant's ways of initiating and of showing competence and distress. These are caregivers who define their own competence by their co-regulatory responsibility and effectiveness, that is, who have an appropriately educated emotional investment in the infant and parents' increasingly autonomous co-regulatory competence.

Support for the effectiveness of developmental care

Increasingly, research is documenting the role of developmental care as an important framework for newborn intensive care delivery resulting, for the most high-risk group of very low birthweight ventilated infants, in improved medical outcomes such as decreased intraventricular hemorrhage, reduced severity of chronic lung disease, improved growth, earlier discharge, and significantly reduced hospital costs (Als et al, 1986; Becker et al. 1991; 1993; Als et al, 1994; Fleisher et al, in press). Increased protection of and support to the developing nervous system by adapting the environment to the individual capacities of the infants appears to result in improved patterns of brain functioning (Als et al, 1994). This has also been demonstrated for healthy preterm infants receiving developmental care. Their brain functioning patterns were found to be significantly more similar to full-term infants, and very different from those of preterm infants not receiving developmental care (Buehler et al, in press). It appears that developmental care may differentially protect the frontal lobe, a finding of interest, given that the neuronal organization of this region occurs relatively late in the developmental sequence (Huttenlocher, 1984). These findings are particularly encouraging since the frontal lobe is implicated in organizing executive functions of the brain—attention, state regulation, planning, prioritizing, and monitoring. These are the functions which have previously been found to be particularly vulnerable in the preterm infant (Als et al, 1989; Hack et al, 1994)..

Challenges of implementing developmental care nursery-wide

Over the past five years, we have collaborated with colleagues from five hospitals on the National Collaborative Research Institute for Early Childhood Intervention (NCRI-ECI), a multi-site study funded by the US Department of Education, to examine the effectiveness of the developmental approach (Als et al in preparation). In addition to an experimental investigation, this study provided the opportunity to examine questions of implementation—to explore the reasons that clinical insight of the individual practitioner about the importance of developmental care is not easily translated into larger scale, nursery-wide implementation. A senior neonatologist anticipated the dilemma 25 years ago as he recalled his first awareness of developmental care:

Let me tell you about the first developmental nurse. She seemed to do better at gavage feeding than the others. I watched how she fed the babies. She put the tube in and then she'd stroke around the baby's belly, just like she was calming him. We noticed the babies fed a lot better, didn't spit up as much, and gained weight better. So we noticed that, and our thought was, why doesn't everybody do it?
(Gilkerson & Als, 1995, p. 20)

This nurse's caregiving demonstrates her intuitive association between infant behavior and her caregiving practices, a link which resulted in improved outcome. Parents often ask: Why does developmental care need to be proven? Isn't it obvious that this care is what the infant and the family need? Nurses and physicians have commented that it is just common sense to make the baby and family as comfortable as possible. What makes developmental care so challenging? Why is it not practiced by everyone? And how can nursery staff be supported to move toward this new framework for care?

As part of the NCRI-ECI study, interviews were conducted with over 160 NICU professionals and family members to explore issues in implementation. It appears that many of the challenges are tied to the nature of the developmental approach itself—the fact that it is theory-guided, relationship-based, and systems-oriented (Gilkerson & Als, 1995).

The key concept of the developmental care framework is the concept of co-regulation, based in an evolutionary, theoretical framework of a neurobiological basis for the social nature of humans. The concept of co-regulation is central to the understanding and support of the relationship between the infant and family in the NICU. Implementing a theory-guided rather than a procedurally-driven approach is challenging in any setting; it is especially challenging in acute care environments

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which are, by tradition and necessity, oriented to standards, protocols, and caregiving routines (Gilkerson, 1990). A co-regulatory framework to care requires that the caregivers be mindful of others and, therefore, be reflective about their own actions and ways of being. Reflection as a framework for practice is not typically articulated in action-oriented, intensivist care work. Yet, with the move toward developmental care, reflective practice, by necessity, becomes a focus.

The role of reflection in the implementation of developmental care has been spelled out recently in more detail (Gilkerson & Als, 1995). The ZERO TO THREE Work Group on Supervision and Mentorship defines reflection as "the continuing conceptualization of what one is observing and doing" (Fenichel, 1992, p. 10). Reflection provides a framework for "knowing-in-action" (Schön, 1983; 1987) and shifts focus to include self-knowledge as a necessary professional competency (Bowman, 1989). Since the core of developmental care is the observation of infant behavior and the formulation of caregiving plans based on that observation, Schön's (1983) conceptualization of "reflection-in-action" is particularly apt. Developmental care implementation requires "the processes of 'feeling,' 'seeing,' and 'noticing' what it is you are doing; then learning from what you feel, see, and notice; and, finally, intelligently, even intuitively adjusting your practice" (Tremmel, 1993, p.438). Tremmel (1993) points out that to be open to reflection one has to change the way one's mind works, a challenge for any trained professional caregiver. An experienced nurse described how difficult, yet rewarding, it was to let go of familiar formulas that have shaped practice: "So much of nursing is doing routine things in a routine way. I used to suction every 3 hours, regardless. Now I think, 'Who am I suctioning for—me or the baby?'...I knew what to do before, now I know why." (Gilkerson & Als, 1995). Developmental care requires the encouragement of flexible minds, comfortable with "doing, learning, and coming to know" (Tremmel, 1993, p.438).

Relationships imply connections. Nurses who embrace a developmental approach acknowledge the connections between themselves and the infants and families for whom they care.

I used to think "I'm going to go in, put a suction catheter down the endotracheal tube, I'm going to change a diaper, I'm going to flip him, I'm going to close the door, and I'm going on to my next job and I'm not going to look in again until I have more tasks to do to him." I knew what I had to do that day but I really didn't have a sense of who the little person was I was relating to.

My mindset is different now. Now I think when I go into the isolette, it's almost like a visit. I'm coming in to communicate with you [baby] and the baby's going to communicate back with me. I'm going to observe and assess the infant and there are some things I have to do but I'm going to watch what he's telling me and adjust what I have to do given the cues that he's giving me . . . I feel connected, so much more in tune. (Gilkerson & Als, 1995, p.24)

This new connection with the infant strengthens the capacity to nurture relatedness between parent and infant.

Before I learned about the developmental approach....[in talking with parents], I focused on fixed traits like he has blue eyes . . . I didn't talk about . . . his humanness. Now I think I facilitate parents seeing their infant like a family would, knowing their baby at home. (Gilkerson & Als, 1995, p.24)

Yet work with relationships is demanding. The responsibility of connectedness can be threatening, especially to caregivers whose identity is tied to competence with technology and science. A basic tenet within the mental health disciplines is that work with relationships requires ongoing supervision, a component which is typically absent in traditional NICU settings, as it is in many other infant care settings. The ZERO TO THREE Work Group on Supervision and Mentorship (Fenichel, 1992) has defined three essential elements of supervision: regularity, collaboration, and reflection. In this framework, supervision is a relationship for learning where time is set aside on a regular basis, with an experienced and trusted professional, to explore the "imperfect processes" of professional practice (Belenkey et al, 1986) and one's own responses to the work. Shanok (1992) describes supervision as a place where "strengths are emphasized and vulnerabilities are partnered" (p.40). In the NICU the professional is continually called upon to make decisions and to act. In supervision, Shanok explains, learning is by reflection which then translates back into more thoughtful, mindful action. All NICU professionals should have access to opportunities for reflective supervision; at a minimum, members of the core developmental team should have the opportunity for individual supervision to strengthen

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their self-awareness and their capacity to engage in and support relationships.

The relational nature of developmental care is also evident in the process of implementation. Because of the nature of intensivist care and interdependence among the caregivers, changing patterns of NICU care is a complex endeavor which often requires considerable skill in social negotiation and collaboration. For example, allowing an infant to complete a full sleep-wake cycle without interruption may affect the timing of the physical examination by the attending physician and residents, medical procedures carried out by the fellows, specialty consultations, laboratory work, respiratory or other therapies, or even the services of the housekeeping staff. The developmental team must design a process which considers multiple perspectives and includes all involved. This is particularly important when changes affect what Scheinfeld (Personal communication, 1993) has called the "flow of activities." In a study of staff emotions in a psychiatric hospital setting, Scheinfeld found that the way a staff person typically does a routine or procedure has psychological meaning to him. The "flow of activity" gives comfort, a sense of control, a sense of being able to effect outcome. When this flow is interrupted, there can be a chain of emotional responses—anxiety, loss, anger. Because the developmental approach seeks to provide care with rather than to infants, the developmental model must be implemented in a parallel fashion, that is, with rather than to staff. For implementation to succeed, an experienced nurse manager explained, the unit must work simultaneously towards two goals: "We must integrate developmental care into practice and build collaborative relationships at the same time." Therefore, one of the most important capacities for the developmentalist in the intensive care setting is the ability to stay engaged with others despite apparent differences. Bettelheim (Bettelheim & Rosenfeld, 1993) states that when we don't know how to perceive another's behavior we "start with the assumption that the reasons or motives that lie behind his actions...seem good to him" (p. 107). "We must always proceed on the assumption that the other person's thoughts and actions are worthy of being considered in the most positive way possible" (p.119). Staying connected in this way requires a high degree of intrapersonal and interpersonal knowledge and skill, another reason why the provision of ongoing reflective supervision is essential.

In the beginning days of implementing the developmental approach in one nursery, a staff nurse remarked that she often felt torn between the needs of the baby and the needs of the staff. The polarization which this nurse experienced results in part from the press of clinical work and the lack of time to consider the needs and perspectives of all involved. In the NCRI-ECI study, we found that it was essential for the developmental team and the nursery leadership to set aside regular opportunities to reflect upon the process of implementation to slow down the process and to consider all aspects of the evolution toward developmentally supportive care. A model for this process is described elsewhere (Gilkerson & Als, 1995).

The relational nature of developmental care, by definition, makes it systems-oriented. As noted above, a change in any one part of the system has effects for the entirety of the system. Changes in the larger system, in turn, affect the dynamics within the smaller unit. As part of the periodic review of the implementation process, it is important to step back and take the pulse of the larger nursery system (Gilkerson, 1993) in order to understand the unit culture, particularly patterns of communication and conflict management (Shortell et al, 1991); critical events affecting the unit; and, most importantly, the unit's identity and sense of distinctive competence (Cooperrider & Srivastva, 1987). Fostering of change and growth, therefore, must always keep in mind the two interrelated and mutually catalyzing components of the system's growth and of the growth of individuals within the system.

Summary

The biggest change in NICU care, the move from protocol and procedure-driven to relationship-based developmental care is gaining momentum. A methodology for teaching about the observation of the infant's behavior is now available. Research documenting the efficacy of the approach is increasing; insights into individual and systems supports needed to ensure success and effectiveness of the approach are becoming increasingly understood and articulated. As the NICU begins to define itself not only as a physical care setting, but also one that supports emotional well-being, the infants and families in its care will gain. Moreover the sense of effectiveness and satisfaction of the professionals in the setting will also increase.

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Newborn Intensive Care Units Pioneer Family-centered Change in Hospitals across the Country

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The baby girl delivered by emergency Cesarean section was like so many infants who begin their lives in newborn intensive care: born only 26 weeks after conception, Jessica needed immediate, significant life support. She was placed on a ventilator and rushed from the delivery room and from her mother within minutes of birth. But unlike many premature infants who struggle with serious lung infections and other major complications in the weeks after birth, Jessica made rapid and steady progress entirely free of the typical complications of preterm delivery. Within two weeks, she was off the ventilator, and a week later she no longer needed supplemental oxygen. She started nipple feedings earlier than expected, gained weight steadily, and at just 36 weeks after conception, Jessica went home with her family as a healthy, growing, infant with a strong prognosis for a healthy future.

What explains this baby's quick, complication-free recovery from intensive care in the first days and weeks after birth, while so many critically ill newborns face a much more difficult struggle to survive? Dr. gretchen Lawhon, director of the perinatal-pediatric developmental program at the Children's Medical Center of Northwest Ohio, attributes much of the baby's success to important family-centered changes taking place in conjunction with the individualized developmental approach to newborn intensive care. These changes place families at the center of care, acknowledging that parents and other family members are the most important people in a baby's life and are absolutely critical to his or her well-being, especially when infants need life-saving technology and the help of skilled professional staff to survive.

Family-centered care promotes practices that nurture the strong bonds that begin between infants and their families before birth and supports those relationships throughout the intensive care experience.

Jessica's parents were included in her care from the moment of delivery. Although her mother was not able to hold the baby immediately after birth, she was able to see her briefly. Jessica's father followed her into intensive care and moved freely between the infant and her mother during the first few hours, supporting both of them during this critical period. The next day her eight-year-old brother spent time with his new sister. Staff members explained the baby's condition to him, answered his questions, and told him about their plans to support Jessica, him, and their parents. At first, medical staff met daily with the parents, reviewing plans for care, anticipating problems, listening to their concerns, and supporting their decisions on issues such as breast-feeding. As the baby's health progressed, these meetings occurred weekly. Throughout Jessica's intensive care experience, her parents spent a considerable amount of time with her and became comfortable holding, feeding, and diapering her while she was still in the hospital.

"It is impossible to overestimate the power of a parent's presence," says Dr. Lawhon. "I've seen this again and again. When two critically ill infants have the same clinical diagnosis, the one who has family present, pulling for him or her and actively participating in care, will almost always do better."

While the national political debate on health care reform has stalled over issues of financing and organizational structure, and managed care is driving structural and economic changes in many communities and states, health care professionals and families in hospitals across the country are working closely together to promote significant change in the ways that infants, children, adolescents, and their families experience and participate in their own health care.

Increasingly, newborn intensive care units (NICUs) actively promote this family-centered change. Physicians, nurses, and families collaborate intensively to improve the quality of care, contain spiraling costs, meet important emotional and developmental needs of infants and families, and improve medical and developmental outcomes.

What is family-centered care?

Family-centered care offers a new way of thinking about the roles of families and health care providers. Family-centered providers recognize that over time, the family has the greatest influence over an infant's health and well-being. They assume that all families, even those who are struggling with very difficult life circumstances, bring important strengths to their infant's health care experiences.

Family-centered care providers acknowledge that emotional, social, and developmental support comprise integral components of health care. This approach empowers families and fosters independence; supports family caregiving and decision making; respects family choices; builds on family strengths; and involves families in all aspects of the planning, delivery, and evalua-

tion of health care services. Information sharing and collaboration between families and staff are cornerstones of family-centered care (Institute for Family-Centered Care, 1995).

Why are NICUs becoming more family-centered?

Family-centered change has developed in response to a growing sense that the care of preterm and critically ill infants, while technically proficient, often fails to meet important emotional, developmental, and practical needs of babies and their families. Also, traditional approaches to neonatal intensive care often foster dependency in families, interfering with the infant-family relationship and with the family's ability to provide care at home and in the community. NICUs employ some of the most sophisticated technological advances in modern medicine. While the skilled professional use of this technology has enabled health care professionals to preserve and extend the lives of premature and critically ill infants, it has sometimes been delivered without awareness of the impact of treatment on developmental needs and long term relationships. Parents have expressed the dilemma this way:

In spite of staff's efforts, I couldn't feel comfortable in the NICU. It is a place to inspire pity and terror in a parent. Hospitals are intimidating. NICUs even more so. I felt I had no control in this situation, I was just a bystander. People were saying very important things to me in a language I could barely comprehend. Although I am normally a very competent person, I felt totally lost. (Rapacki, 1992, p. 378)

In contrast, when NICU staff create a family-centered atmosphere for care, families know they provide essential care for their infants. For example, one young mother said, "Nurses taught me to do all my baby's care. They were just there to do his care when I wasn't there."

Cost also drives family-centered change in the NICUs. Traditional approaches to hospital care are expensive, and NICUs use a high proportion of a hospital's resources. Infants under the age of one month, primarily NICU patients, account for nearly one-quarter of the patient days in a children's hospital and 27 percent of hospital charges. When a family participates effectively in an infant's NICU care, infants spend less time in the hospital, transition to home more easily, and experience fewer hospital readmissions. All of these factors affect the cost of care.

Other forces driving family-centered change in NICUs include:

Individualized developmental care. This in-depth, systematic approach to neonatal intensive care incorporates the strong belief that "family-centered care and developmental care are inextricably linked" (Als, personal communication, 1992). The data emerging from the developmental care research documents the efficacy of this approach for improving medical and long term developmental outcomes and minimizing the cost of care.

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Early intervention. The availability of effective early intervention programs for infants and toddlers with special needs and their families has grown in recent years. As community-based early intervention providers and NICUs work more closely together, hospital staff become more aware of infants' long term developmental needs, the value of family-to-family and other family support, and the importance of facilitating the transition from the NICU to the community. In some states, NICUs receive funds and personnel to further the implementation of family-centered, developmental care and to improve coordination between NICUs and community-based early intervention programs.

Family advocacy. Increasingly, families are voicing their concerns and priorities about traditional approaches to NICU care. Awareness that families are the infant's primary caregivers is growing among professionals. Families' contributions to changes in maternity care and services for children with special needs demonstrate that families bring valuable expertise to planning, implementing, and evaluating NICU policies and practices.

Quality improvement. As hospitals strive to assure the quality of services and satisfy their primary consumers, they are intensifying their efforts to respond to the identified needs and priorities of infants and their families. The collaboration central to family-centered care pro-

vides important continuous feedback on the quality and appropriateness of services from those who receive them.

What changes does family-centered care bring to NICUs?

Family-centered thinking profoundly changes how professionals and families work together and care for infants in critical care settings. It also spurs important changes in the design and physical environment of NICUs to provide more supportive care for infants and their families.

Individualized developmental care and family/professional collaboration

Through the newborn treatment approach known as individualized developmental care, health professionals increasingly recognize that even the most vulnerable preterm infants have innate strengths and individual developmental needs. Individualized developmental care builds on each infant's emerging competency to achieve stability and shape his or her own development. This approach to care results in lower morbidity, reduced complications, shorter hospital stays, lower costs, and better long term outcomes (Als, H., Lawhon, G., Duffy, F.H., McAnulty, G.B., Gibes-Grossman, R., & Blickman, J.G., 1994).

Those who practice individualized developmental care emphasize the importance of working closely with family members to help them appreciate their infants' individuality, humanity, and very real strengths in an environment that is often frightening and dehumanizing.

With a family-centered approach, staff no longer see families as visitors to the NICU, but as their infants' primary caregivers and essential partners with staff. Those who practice individualized developmental and family-centered care understand that they are not substitute parents, but facilitators whose job is to help parents and other family members assume their natural role as primary caregivers. They recognize that infants and parents come to NICUs with strong relationships developed during pregnancy, and that NICU staff should nurture and protect that vital bond, minimizing the harm that the necessary technological interventions can inflict on it.

In addition to working closely with individual families, family-centered NICUs systematically involve family members in policy development and program planning by inviting them to participate in advisory councils, to facilitate peer support, to serve as educators for staff and professionals-in-training, to develop linkages with community agencies, and to participate in other collaborative activities. By involving families at this level, NICU professionals gain valuable insight about how families experience care, what they need and want, and how the NICU can continuously improve services to accommodate and support them.

One of the most important and controversial aspects of family-centered change involves creating 24-hour-a-day open visiting guidelines. With such guidelines, family members, rather than hospital staff, define who their "family" is and decide the length and time of visits. Currently, many NICU visiting policies claim that visiting hours are open, then list exceptions when the unit is closed, such as during changes of shift, rounds, admissions, emergencies or some procedures.

When NICUs and other hospital units gain experience with truly open policies, previously held beliefs about issues such as confidentiality begin to change. Nurses and physicians who practice family-centered care discover that they can conduct rounds and other reporting procedures in discreet ways that respect families and preserve their confidentiality. When complex issues require discussion, sit-down rounds in other locations usually meet the need more appropriately than extended bedside discussions and help reduce noise levels at the infant's bedside.

Some NICUs restrict visiting hours primarily to relieve staff of the need to accommodate family members during part of the day. Unfortunately these NICUs do not recognize the vital role of families to infants' health. NICUs struggling with visiting issues need to re-examine staff priorities—recognizing their primary responsibility to serve infants and families—and explore other ways to meet staff members' legitimate need to deal with the stress of caring for critically ill infants.

Family-to-family support

Families who share the stressful experiences of critical care can support each other in tremendously valuable ways. To encourage family-to-family support, family-centered NICUs promote formal and informal contact among families. Their staffs look for ways to facilitate helpful one-on-one relationships between families with similar backgrounds or parallel medical situations. This can include recruiting and training families of NICU "graduates" to share their experiences with families in the hospital, offering both practical and emotional support. Family-centered NICUs also help families connect to family-to-family support networks in the community.

What barriers do individuals and institutions face as they implement family-centered care?

Many individuals and most organizations struggle with change toward family-centered care. Such change requires health care professionals and family members to think and act in ways that counter long-held beliefs about their roles and responsibilities. At first, family-centered practices may also seem to require more staff

time and energy and disturb carefully devised policies and practices. Barriers to change include:

Staff attitudes. Traditional NICU training and procedures have encouraged professional staff to think of themselves as infants' primary caregivers in intensive care. Learning to share responsibility for the babies' health and facilitate family caregiving can be very difficult, particularly under the stressful conditions of critical care. Until they have direct and positive experiences sharing responsibility with families, professionals may feel that working with family members will only add to an already burdensome work load.

In fact, family-centered practices ultimately lighten staff loads. As a nurse who learned to practice family-centered care at Phoenix Children's Hospital has said, "[Working with families] is more work up front, but it gives added energy and you see added value. In the end, you do less care because families are able to do it."

Other stresses may also make staff reluctant to make family-centered changes. Because they must perform difficult and sometimes painful procedures on fragile newborns, some NICU staff find that focusing on the technological aspects of their work is less stressful than relating to families and thinking about the emotional needs and feelings of the tiny infants they work to save.

Maternity care. In some hospitals, prenatal and maternity policies for pregnant women at risk for premature delivery foster dependency and low self-esteem among these women. For example, some hospitals designate nap times or set visiting policies that restrict times when families can be together. Health care providers often develop care plans without incorporating the preferences and concerns of a woman and her family. Schedules designed for staff convenience without thought to women's needs and priorities, failure to explain medications and procedures, and the absence of information about what to anticipate with high risk pregnancies further rob expectant mothers of the belief that they can make decisions related to their own bodies and care competently for their newborns.

Family reluctance to speak up and participate. The frightening and intimidating nature of intensive care makes many families reluctant to speak up and assert themselves. Because most families have little experience working as partners with health care professionals, they need support in order to do so effectively in such a stressful environment.

Unit design. The physical design and space allocation of many NICUs has been determined by the need for equipment and staff without sufficient regard to including, supporting, and encouraging families during their infant's care. The entrances to NICUs often create negative first impressions that intimidate families. Noisy and brightly lighted units frequently lack bedside space for families, places to spend quiet time with their infants, places for families to learn and practice caregiving, rooms to confer with others on the health care team, and lounges for rest and relaxation with family or friends. While important family-centered changes can occur in an unsupportive physical environment, inadequate or poorly designed physical spaces severely limit, and can even prevent, full implementation of family-centered care.

Restricted visiting policies and the myth of endangering confidentiality. Restricted visiting hours and institutional definitions of family that limit who may visit fail to recognize the diversity of families, support their needs, and honor the central role they play in infants' lives. The mistaken belief that open visiting and full information sharing policies will endanger privacy and confidentiality prevents some professionals from fully implementing family-centered policies.

Lack of staff knowledge about developmental needs. Highly trained staff who deliver sophisticated technological and medical care may lack knowledge about the unique developmental and emotional needs of fragile preterm infants. Their limited knowledge of infant development may prevent them from effectively helping families learn their infants' developmental cues. Further, staff may not fully appreciate the importance of a strong infant-family relationship to the child's long term health and well-being.

Strategies for change

Making the change to family-centered care requires a long and evolutionary process in most hospitals. Small changes undertaken experimentally can have a powerful positive impact on a unit and, ultimately, on an entire institution. When NICUs become centers of change that focus the energies of motivated staff and families, they also become catalysts for broader change toward family-centered policies and practices throughout a hospital. Several strategies can help begin the process of change or energize changes already begun. These include:

Develop a statement of shared vision. Vision, mission, and philosophy of care statements set the tone and direction for a hospital and its maternity and newborn intensive care services. Effective vision and mission statements convey an explicit commitment to family-centered care; emphasize the beliefs, values, and priorities of women and their families as key considerations in shaping maternity and newborn services; and convey respect for families and their primacy in their infants' lives.

For example, the vision and mission statements adopted by the staff in the developmental pod of the NICU at **Phoenix Children's Hospital** in Phoenix, Arizona, include the following language: "We will achieve success through our dedication to patient and family as a priority, while managing care with a team approach . . . Our main focus is on optimal developmental out-

come for our patients and maximum family involvement and education." These statements help guide decisions, policies, and practices at the NICU.

Conduct a self-assessment. A detailed examination of the NICU's philosophy, environment, policies, and practices, performed by an interdisciplinary team including families who have experienced care in the NICU, can help identify and prioritize areas for improvement and measuring progress. A useful assessment includes such questions as:

- Does the NICU have a written philosophy of care statement that respects the pivotal role of families in promoting the health and well-being of their infants?
- Does the NICU's environment convey that it is a caring place for infants and families?
- Does the NICU environment provide adequate privacy for families—at the baby's bedside, for breast feeding, and for consultations with health professionals?
- Do NICU position descriptions and performance appraisals clearly articulate the necessity of working in respectful and collaborative ways with families?
- Are families involved in caring for their infants from the very beginning and throughout the hospital stay?
- Are documentation procedures and forms developed in consultation with families?
- Do staff interact respectfully with all families?
- Do families who have experienced the NICU participate in developing and evaluating its policies, programs, practices, and unit design?

The self-assessment inventory included in the resource list accompanying this article serves as one tool for conducting such an analysis.

Creating a variety of formal and informal ways to collaborate with families. When consulted and included, family members with experience in NICUs make valuable contributions to program and policy development. To build collaborative relationships with families at this level, NICUs can establish family advisory councils, hire family members as liaisons or consultants, and include families on planning teams for facility design and construction.

For example, **Hermann Hospital** in Houston, Texas, has created a parent advisory group and a family-centered care committee for the NICU. These groups help address issues of concern to families. To alleviate families' confusion on first entering the NICU, they have developed three videotapes to explain how staff members function in the NICU and what the equipment is for. They have also created a "communication book" specifically for families, to supplement the medical chart as a way for family members to communicate with nurses and physicians. The groups are also seeking ways to better involve teen-age parents in program planning and evaluation for the NICU.

Cedars Sinai Hospital in Los Angeles works closely with families in the NICU through Good Beginnings, a parent-to-parent support group that has operated in the hospital since 1979. Director Dorothy Williams, once a parent in the NICU, now coordinates family-to-family contacts and trains parent volunteers to provide one-on-one support to family members during their infant's hospital stay. The program includes weekly meetings for parents and offers financial support for transportation and babysitting to those in need so that they can spend more time with their babies. Because the community is culturally diverse, Good Beginnings is working to diversify its team of volunteer and peer supporters so that they can better address the individual needs of families in the NICU. Good Beginnings members also serve on policy groups such as the hospital's Newborn Joint Practice Committee and the Life Support Advisory Committee.

Conduct a research demonstration project. One strategy for promoting family-centered change when there is some resistance to change is to create a pilot study with a small group of professionals and family members within a NICU. Having a limited research project within the unit designed to demonstrate the value of family-centered practices can facilitate innovation in a non-threatening way. Skeptical staff members become more open to change as they observe over time the positive implementation of new practices.

In April 1992, a team of nurses at **Phoenix Children's Hospital** in Phoenix, Arizona, undertook a two-year study to test the effectiveness of individualized developmental, family-centered care, compared with standard NICU practice. The team practiced developmental care with infants and their families randomly assigned to a five-bed pod within the hospital's 45-bed NICU. Preliminary results of the study indicate that infants who received individualized developmental care with high family involvement spent less time on ventilators, gained weight more rapidly, and had shorter hospital stays.

Parents in the experimental pod also rated the NICU experience more highly than those receiving standard care. "This approach is a great satisfier of families and staff," says Carol Vecchi, family care coordinator for the nurseries at the hospital. "We know it's better for families."

The study was so successful that the unit has created three new collaborative care teams to serve an additional three pods and 17 more beds. A multidisciplinary group is also exploring ways to modify lighting and other design elements in the unit.

Staff who participated in the study report that the experience gave them valuable opportunities to re-examine their roles and learn new ways to integrate families into their infants' care. One staff member said of the experience: "I thought I always involved the parents, but I only involved them on my terms, not theirs."

Staff reported that working as a team and collaborating with families took extra time at first, but ultimately lightened their load as parents and other family mem-

bers began to take primary responsibility for their infants.

Institute NIDCAP training. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) educates and trains health care professionals to structure programs of care based on individual infants' strengths and developmental needs, organized in ways that support individual infants and their families. Those who practice individualized developmental care work to support and nurture the parent/infant relationship and build relationships with other professionals who can provide support for the infant and family after discharge.

The Children's Medical Center of Northwest Ohio in Toledo has recently created a position devoted to implementing individualized developmental and family-centered care for the NICU, pediatrics, and perinatal services. This position is held by developmental specialist Dr. gretchen Lawhon. She conducts NIDCAP training in the NICU and works with staff to help integrate families into their infants' care as early as possible.

Incorporate family-centered philosophy into physical design and integrate families into the design planning process. The square footage necessary to accommodate state-of-the-art technology, treatment methods, and multiple, specialized staff forces many hospitals to expand and redesign the spaces allocated for newborn intensive care. Whether planning a limited renovation or significant new construction, providing adequate space to meet family needs should be a top priority.

Even relatively limited renovation and redecoration can make a significant difference to families. For example, the Children's Medical Center of Northwest Ohio plans to renovate its NICU to create a more welcoming and supportive environment for infants and families. All of the rooms will then have dim lights and muffled sound. The unit's two entrances will create welcoming first impressions for families. Planners are also exploring ways to create better space for families within the NICU.

Planning for renovation or new construction creates important opportunities for hospital staff, design professionals, and families to work together, rethinking the ways NICUs serve and support infants and their families and planning more appropriate NICU environments. Integrating family members into the planning process can help NICUs carry out the principles they have articulated in vision and mission statements. For example, one NICU has developed a vision for its special care nursery that includes the following points:

• *We believe that the most essential component in the long term outcome of an infant is the parent-child relationship.*

• *We believe that the parents do not "visit" their babies in the Special Care Nursery; rather, they provide care and parenting.*

Department of Photography, Denver Children's Hospital

• *We will create an environment that supports and protects the baby's individual abilities and the family's emerging parenting behavior.*

(Alta Bates Medical Center, Berkeley, California)

These ideas have profound implications for the design of physical space. When such family-centered values are taken seriously, they shape fundamental design decisions, suggesting ways that the facility itself can support families. A design planning team that includes family members is more likely to make the important connections between these values and the often difficult design decisions that also include cost, medical and technological requirements, and other factors.

Institute home visiting. Some innovative perinatal programs now include home visits to families to improve pregnancy outcomes and reduce health care costs. Sinai Samaritan Medical Center in Milwaukee, serving largely an inner city population, instituted home visiting as part of a statewide prenatal care coordination program. Inpatient nurses and medical students in their obstetrical clerkship are encouraged to spend a day with an experienced home care nurse. The home visits not only help pregnant women receive consistent prenatal care, they also increase students' and profession-

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als' respect and appreciation for the strengths of families, their deep commitment to their children's welfare, and the difficulties they face in caring for them. A similar strategy could be valuable for NICU professionals and families.

Provide family-centered transitional care. Positive experiences supporting families in transitional care can influence thinking and practice in NICUs. In the Transitional Care Center (TCC) of **Rainbow Babies and Children's Hospital** in Cleveland, Ohio, family-centered practices have significantly improved outcomes and shortened hospital stays. Special features of this unit include a separate living and sleeping area for each baby and his or her family and a common area with cooking and eating facilities. Now planning a major hospital construction project, the team is expanding the TCC and applying the innovative concepts from the TCC to the new NICU.

Review maternity programs to ensure that policies and practices support women's choices, help them develop competency and self-assurance, and help them anticipate and prepare for the complications of a premature or difficult delivery.

Connect with early intervention programs. Build on the developmental perspective of early intervention professionals in NICUs and integrate them into planning and advisory groups, support networks, and other mechanisms for professional/family collaboration and collaboration between hospital-based and community-based providers.

Rethink staffing patterns in NICUs. A NICU is a difficult place for residents to gain independent experience. The complex nature of care delivered in NICUs requires more continuity and expertise than most physicians-in-training can reasonably provide on their own. Advanced nurse practitioners and physician assistants can provide technically proficient care and offer more continuity for families. Developmental specialists and parent liaisons also bring important expertise and perspectives to a NICU team.

Conclusion

As professionals and families gain experience with full collaboration and discover the rewards of working together, family-centered policies and practices profoundly change the health care experience for infants, children, adolescents, and their families in hospitals. NICUs working to fully integrate families into their infants' care become models of family-centered care for other NICUs and other hospital units.

In a changing health care environment in which hospitals face increasing pressure to cut costs, improve quality, and more effectively meet the needs of consumers, family-centered care helps institutions, professionals, and families provide high quality, cost-effective care for one of our most vulnerable populations—premature and critically ill infants.

The fundamental change in thinking that places the needs of individual infants and their families at the very center of health policy and practice is not easy for many health care institutions and professionals, and it takes time. But once health care providers see other family members as the child's primary caregivers, especially during hospitalization, the process of family-centered change can be highly rewarding to professionals and vitally important to the long-term health of newborns and the people who matter most to them—their families.

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- On-site training and technical assistance for NICUs embarking on a process of family oriented change
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- Publications—*Essential Allies: Families as Advisors* and *Hospitals Moving Foward with Family-Centered Care.*
- Newsletters—*Designing for Child Health* and *Advances in Family-Centered Care.*
- Videotape—*Designing for Family-Centered Care*
- Seminars—*Hospitals Moving Forward with Family-Centered Care* for parent/professional teams, and *Innovations in Medical Education* for physical educators

The Colorado Consortium of Intensive Care Nurseries: Spinning a Web of Support for Colorado Infants and Families

Joy V. Browne, Ph.D. and **Suzanne Smith-Sharp**

Supported by the Interagency Coordinating Council for the Individuals with Disabilities Education Act, Colorado Department of Education

A spider's web is stronger than it looks.

Although it is made of thin, delicate strands, the web is not easily broken.

However, a web gets torn every day...and a spider must rebuild it when it gets full of holes.

On foggy mornings, Charlotte's web was truly a thing of beauty. This morning each thin strand was decorated with dozens of tiny beads of water.

The web glistened in the light and made a pattern of loveliness and mystery, like a delicate veil.

There, in the center of the web, neatly woven in block letters, was a message.

"Have you heard about the words that appeared in the spider's web?" asked Mrs. Arable nervously.

"Yes," replied the doctor.

"Well, do you understand it?" asked Mrs. Arable.

"Understand what?"

"Do you understand how there could be any writing in a spider's web?"

"Oh, no," said Dr. Dorian. "I don't understand it. But for that matter I don't understand how a spider learned to spin a web in the first place. When the words appeared, everyone said they were a miracle. But nobody pointed out that the web itself is a miracle."

"What's miraculous about a spider's web?" said Mrs. Arable. "I don't see why you say a web is a miracle—it's just a web."

"Ever try to spin one?" asked Dr. Dorian.

from *Charlotte's Web*, by E.B. White

Neonatal intensive care nurseries (NICUs) across the country are struggling to become "family-centered." But while they embrace the morality and logic of the values of family-centered care, NICU staff find that it can be extremely difficult to bring about the changes needed to implement this philosophy.

How can a NICU move toward developmentally supportive and family-centered care during these days of health care "reform," and the associated "downsizing," "rightsizing," and reorganization? And even if a single nursery can take on this challenge successfully, could almost all the NICUs in a state work collaboratively toward a common goal of providing individualized, developmentally supportive, and family-centered care to high-risk and special needs infants and their families? The experience of the Colorado Consortium of Intensive Care Nurseries demonstrates that a statewide movement can provide a strong web of support for changing the way that intensive care is provided to infants and their families. This experience also provides valuable insights into the process and progress of change within individual NICUs.

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Evolution of the Colorado Consortium

The initial sparks for the consortium began in the late 1980s, when NICU professionals began to read about developmentally supportive care in the literature, attend meetings on the topic, and incorporate new information into their clinical practice. A training center for the Newborn Individualized Developmental Care and Assessment Program (NIDCAP, see box) had also been established in Denver in 1990. The availability of the training center for consultation and education in developmentally supportive care furthered progress within individual nurseries. Eight of Colorado's 20 NICUs committed themselves to training a few of their staff in this approach.

Nurseries that had invested in NIDCAP training soon recognized the need for additional support and consultation in order to implement the recommended approaches and to work toward nursery-wide changes. Because the eight nurseries that had received NIDCAP training originally were working toward a common goal, it seemed logical to develop a system of support for this group. Newborn Hope, Incorporated, a Colorado philanthropic organization that supports education and research for professionals who care for infants with respiratory complications in newborn intensive care units, provided support for the initial consortium efforts.

The consortium has become a statewide network of level II and III neonatal intensive care units which pro-

Definitions

Developmentally supportive care is a method of caring for fragile infants according to an evaluation of the individual infant's needs and strengths. The infant is viewed as an active contributor to his or her own care. Modification of the newborn intensive care environment and caregiving activities are then individualized accordingly. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) provides a framework for assessment and individualized intervention for preterm and high-risk infants (Als, 1983). Infants who receive developmentally supportive care using the NIDCAP approach have improved medical, developmental, and family interaction outcomes as compared with infants who do not receive this modified care (Als, et al., 1986, 1994; Becker, at al., 1991, 1993; Fleischer, et al., 1995).

Family-centered care is the compassionate, open, total inclusion of the family in the care and decision making process for their baby. In order to accomplish this, a great deal of information must be provided and education must occur, not only regarding medical facts, but also about rights, values, priorities, expectations, and needs of the family. The goal is to *leave the power with the family* — that is, never take it away in the first place, necessitating "empowering" the family at a later date. (Smith-Sharp, definition developed for use in education and consultation with the Colorado consortium). Harrison's principles for family-centered neonatal care (1993) address the difficulties that families continue to have concerning communication, environmental and developmental concerns, pain management, ethical decision making, and follow-up. These principles provide the beginning guidelines for progress toward family-centered care in Colorado's consortium of NICUs. The belief that developmentally supportive and family-centered care are interwoven and inseparable is central to the values of the consortium and is reflected in all consortium efforts.

vides support for nurseries that are striving to implement both developmentally supportive and family-centered care. Consortium staff consists of the project director, a physical therapist, a veteran parent of NICU graduate, and a registered nurse who works in a NICU. All project staff use the NIDCAP orientation to developmentally supportive care and embrace the family-centered care philosophy and are committed to its implementation. Consortium staff support member nurseries through on-site and telephone consultation, dissemination of current literature, and organization of a statewide meeting where nursery representatives can share experiences.

Enthusiasm for early consortium efforts kindled the interest of other nurseries. An innovation grant from the Colorado Department of Education allowed the consortium to welcome any nurseries in the state that were interested in participating. Expanding the consortium was easy. Of the 20 NICUs in Colorado, only three declined to participate, on the grounds that they were too involved in issues such as reorganization or downsizing, or had too few infants in their nurseries to warrant participation. The remaining 17 nurseries were excited about being included and anxious to begin work.

Consortium goals

The statewide consortium's current goals are:
1. to enhance the provision of developmentally supportive care to Colorado infants who begin their lives in intensive care units;
2. to assist each nursery with the implementation of a philosophy of family-centered care; and
3. to enhance the identification and referral of infants needing transition to community-based developmental and family support services, such as Part H of the Individuals with Disabilities Education Act (IDEA) and public health. This process had been initiated in level III nurseries by a Colorado Part H-funded project intitled "NICU Connections," Linda Ikle, project director.

To work toward these goals, each nursery has developed a working team composed, at a minimum, of a consortium staff member, a nurse manager, a staff nurse, a veteran NICU parent, and a community Part H coordinator. Teams welcome additional members, identified for their interest in and commitment to the nursery's goals. Teams commit themselves to meeting monthly with a consortium staff member and to work toward implementation of the goals of the consortium, as well as their own related goals. Consortium staff provide monthly consultation and support, educational resources, and a means of networking among participating nurseries.

Strategies to help nurseries grow

We use three strategies to help nurseries achieve their individual goals as well as the goals of the statewide consortium:
1. frequent consultation with consortium staff;
2. a communication link, to share progress and approaches with other nurseries; and
3. collaboration among nurseries throughout the state to identify and address common issues.

Consultation

On-site consultation has frequently been the catalyst for movement toward a nursery's goals. As a nursery joins the consortium, it participates in an evaluation of its environment, caregiving practices, policies and procedures, and attitudes toward developmental and family support. With this information available, each nursery is assisted in developing its own goals and action plan, taking into account its developmental level (see below)

and available resources. As a nursery progresses, it reviews its goals and action plans to determine what changes need to be made.

Developing a relationship with each nursery team is the major responsibility of consortium staff. As each team identifies its own needs and goals, the consultant individualizes support and provides continuing guidance. In many respects the consultant functions as a member of the nursery team and, as such, contributes to the development of the nursery.

The consortium consultant gets to know and draws out the strengths of each member of the nursery team. Parent and community members often contribute some of the most productive activity and creative ideas, but because these members come from "outside the system," their contributions may be undervalued. The consultant's recognition of these contributions and support for their implementation can go a long way toward making these team members feel valued and their ideas legitimized.

The consultant is also a catalyst for change. To help the team increase its potential for change, the consultant must first understand the unique strengths, interpersonal relationships, and power struggles that are characteristic of the group. Then she must create an environment which encourages all members of the team to contribute and to discuss differences of opinion respectfully. Establishing a level of trust among team members provides the foundation for reflection on current practices or procedures that the team may need to change and for challenging old ways of thinking. Within an ongoing, safe relationship, the consultant is able to persist in offering new information or alternative ways of thinking. The team is able to consider the information, relate it to their own needs and goals, and use it, if they choose, to make change occur.

The consultant helps nurseries identify barriers to progress. A number of nurseries have been coping with severe reductions in staff, physical relocation of the nursery, and similar issues that make working on consortium goals a lower priority. In these circumstances, the consultant helps the nursery team recognize that the issue is not under their control, that it does affect progress toward their goals, and that it is all right to pause and regroup. Several nurseries have gone through the process of identifying an external issue of concern, taking time out to address it, and then coming back to re-evaluate whether the goals and action plan initially established are appropriate to the new circumstances. Almost all nurseries return to the work with a new resolve to progress toward their goals.

Communication

Communication among nurseries helps them to remember that each team is part of a larger effort, working toward similar goals. The consultant broadens each nursery's knowledge base by supplying current literature and other materials, news of educational opportunities, and relevant information about activities in other nurseries. All of the nurseries have generously shared their forms, procedures, and protocols with other consortium participants. A newsletter disseminates additional information.

The experience of open communication among hospitals has prompted nurseries, whose doors have traditionally been closed to outside professionals and agencies, to invite visitors in, in order to share ideas and techniques. As a result, nurses from referring units can give more accurate information to parents whose baby will be transferred to another nursery, and can assure those parents of a similarity of concern for family needs. Representatives of community agencies may make rounds with nursery staff in order to identify infants and families who will need community support services. Enhanced communication among staff of nurseries and community service agencies fosters creative thinking about how to provide family-centered care.

The consortium's annual day-long statewide meeting offers an effective and enjoyable forum for representatives from all nurseries, parent groups, community support groups, and service agencies to discuss issues, strengthen the network, and experience a personal, energizing connection with the consortium. The meeting serves to identify issues of statewide concern and to generate position statements supporting policy change.

Collaboration

Increased communication among nurseries across the state has facilitated collaboration. Collaboration on issues of common concern has united the consortium and influenced statewide change in policy and procedures that affect infants and their families.

Transport between nurseries is an example of an issue affecting families across the state. A critically ill infant may be transported from a community hospital to a distant NICU in order to receive a level of intensive care that is not available in the family's community. But when the infant recovers, insurance or managed care companies may not cover the costs of transport back to the community NICU, thus putting a continuing hardship on families who may not be able to travel long distances in order to be with their baby. When infants are transferred from one NICU to another, parents often have difficulty adapting to the new nursery's procedures, personnel, and environment. Nurses able to help parents "transfer trust" from one nursery to another are not consistently available. Since many of the nurseries in Colorado were concerned about transport issues, the consortium was able to define the issue, determine contributing factors, and make recommendations for change. Statewide forums have been established to identify financial, political, and family factors that need to be addressed. Nursing staff across the state are working to ease families' transition between nurseries by

providing educational information, videotapes, and visits for parents to the nurseries to which their babies will be transferred. The effort is ongoing.

Implementation of Individualized Family Service Plans (IFSPs) in the NICU is another statewide issue that nurseries have addressed collaboratively. Beginning the IFSP process as soon as possible allows infants and families to receive essential support in a timely fashion. A study by consortium staff revealed that most of the key elements needed to initiate an IFSP in the NICU are already in place and well documented in medical records. All Colorado NICUs will soon be able to use a common format for initiating IFSPs; the consortium will educate nursery staff about the importance of family participation at all levels of planning and decision making for their baby.

Factors affecting progress

Nurseries have varied in their patterns of progress toward implementing developmentally supportive and family-centered care, independent of the strategies used to support their growth. Each nursery has its own history, cast of key players, style, and work ethic. The evolutionary process unique to each nursery reflects that nursery's developmental level and trajectory, the key components contributing to work toward their goals, the nursery's style of dealing with difficulties, and the added catalyst for change provided by consortium support.

Developmental trajectories of individual nurseries

Each nursery appears to have its own developmental trajectory. From our experience, we have proposed six stages or levels of development that nurseries negotiate as they achieve the ability to integrate more sophisticated methods of approaching problems, to produce positive change within their settings, and to adapt to new ways of thinking. Each level involves both growth and some turmoil; indeed, increased turmoil seems to be inevitable before a nursery progresses to the next stage. Progress through each developmental level seems to depend on exposure to and experience with the previous level, as well as on internal and external factors that support or disrupt progress to the next level. Some nurseries spend a great deal of time working at each level before progressing to the next; some move quickly through the early levels, only to get "stuck" at a more complex stage.

The first level is that of **awareness.** At this stage, nursery staff become exposed to and excited about the concepts of developmentally supportive and family-centered care, and aware of the potential impact of these concepts on their own practice. This "birthing process" produces a great deal of interest among staff in exploring educational opportunities and ways to implement developmentally supportive and family-centered care. Interested staff expect—and attempt—quick changes in the nursery environment and caregiving practices, oftentimes without the investment of the entire nursery staff. As a result, staff can become overwhelmed by too much information and frustrated by haphazardness in implementation plans. If too many changes are expected without appropriate preparation, turmoil within the staff results.

Marilyn Nolt

The next developmental level appears to be **disruption,** characterized by staff resistance and/or apathy toward change. Emerging from the experience of increased information and expectations, staff demonstrate unwillingness to change their techniques and approaches to caring for infants and families. Policies that were bent to produce flexibility are suddenly tightened again—for example, visitation policies are reviewed to make sure that parents are not "overstepping their bounds" by being present during staff reports. Typically, some staff reject new supportive techniques for infants. For example, a well-intentioned nurse may provide a blanket roll in the bed against which a baby can brace his feet. The nurse on the next shift pulls out the roll, saying, "There's too much stuff in this bed; I can't get to the baby to do my care."

The nursery may then move to the level of **organization,** in which an orderly approach to the implementation of developmentally supportive care is evident. In this stage, nursery staff typically seek information and resources in a systematic manner. They may begin to take on the identity of a "developmentally supportive nursery" and direct many of their resources toward implementing developmentally supportive care. Staff may seek outside consultation, attend meetings on developmentally supportive care, visit other nurseries, and begin to develop an organized plan for education and policy change.

When a nursery has established itself as develop-

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mentally supportive, it may move to a level of **identity,** in which procedures and protocols for delivery of care are developed and implemented. Typically, staff at this level accepts many developmentally supportive approaches as "the right thing to do," but they may still have a less-than-complete understanding of the rationale underlying their behavior or of ways to individualize the approach with infants and their families. At this stage, a prescriptive approach is common: All infants will receive "developmentally supportive care" or "family-centered care"—as defined by nursery protocols. For example, all infants may be positioned in bedding to facilitate flexion and leg bracing ("nests"), without regard to individual babies' age or capability.

At the next level, **integration,** a nursery's approaches to developmentally supportive and family-centered care become more sophisticated and individualized. Staff at this stage may recognize areas of care that need enhancement or expansion, but they may have difficulty moving toward these goals without further assistance. Nursery staff at this stage believe that they have a family-centered approach, but in reality they have only made changes to make parents more comfortable and have "allowed" them to participate in their infant's care. Staff may still be unable to conceptualize infants as collaborators in their own care, or parents as equal partners in the nursery. Sometimes conflict between staff's belief that they can accomplish further goals by themselves and their need to obtain more expertise or consultation may impede a nursery's ability to move to the next level.

At the level of **generation,** a nursery is able to integrate developmentally supportive and family-centered care into its philosophy and practice on a thoughtful and sophisticated level. Staff are able to be flexible and individualized in their practice and can generate new approaches and applications in novel situations. Nursery staff not only provide developmentally supportive and family-centered care within their unit, but are also able draw on their experience to provide expertise and consultation to other areas of the hospital. The operationalization of developmentally supportive and family-centered care is apparent in every area, from individualized care delivery to implementation of professional standards and evaluation procedures.

Components of change

As each nursery in the Colorado consortium has made progress along the developmental levels, we have become able to identify several essential components of positive change.

Key visionaries, people with a passion for implementing developmentally supportive and family-centered care, are essential. Their passion enables them to weather the storms of implementation. Key visionaries can be nursing, rehabilitation, or management personnel who doggedly work toward their goal. A manager who is a visionary—both a "leader" and a "manager"—has frequently been critical to the success of individual nurseries. While a leader participates in planning, implementing, and evaluating a process, a manager's role includes delegating authority appropriately and expecting positive outcomes. A visionary manager's commitment to advocating for the efforts of the group supports collaboration and encourages growth. One consortium nursery was faced with closure, yet the manager pursued activities to the last week of operations. She realized that not only would the infants and families benefit, but the staff who were to be reassigned would also carry the nursery's values and approaches with them to a new unit.

The nursery's commitment to value the individual infant and his or her family in the delivery of intensive care is the second key component of success. Typically, those nurseries that have invested in the implementation of a philosophy which focuses on infant and family needs, rather than on intensive care techniques alone, have been able to make significant progress. These nurseries have also solicited parents as partners in working toward their vision. Several of the nurseries have now established parent advisory groups and consult them about family and infant needs when new policies and procedures are being considered. Other nurseries are systematically revising procedures to include developmentally supportive interventions.

Carefully planned strategies and investment in progress are a third component of success. Several consortium nurseries have committed time and money to developmentally supportive care NIDCAP training for staff. Without exception, these nurseries have shown more progress toward their goals and have been more flexible in incorporating family-centered care than nurseries that have not invested in training.

Nurseries that support their commitment with a strategic plan have made significantly longer strides forward than nurseries without a plan. One nursery, for example, seemed stuck; and participation in meetings was dwindling until the team was able to state its goals clearly and develop a written action plan. Then meeting attendance increased, and the nursery experienced significant growth.

A mutual respect for each team member's contributions characterized the more successful nurseries. Since each of the nursery teams included, at a minimum, a manager, a staff nurse, a parent, and a community Part H coordinator, working toward common goals involved the discussion of widely differing perspectives. After listening to a parent, one team fought successfully to change time-honored hospital policy so that parents could receive a copy of their baby's medical record at no charge. Honoring the views and values of all team members contributes to the richness of the work that each nursery produces.

How nurseries negotiate difficulties

Regardless of the supports provided to help nurseries progress, factors such as changes in management policy, staff changes, staff ratios, and geographic location of the unit strongly influence what happens in the nursery.

In the context of major changes in health care delivery and finance, *management policies* tend to expect more productivity with fewer resources. Typically, hospital management tends to reduce the number of hours allowed for education and planning, for staff and managers alike. Many nurseries are turning to foundations or competitive public grant funding to support staff education and purchase supportive equipment. Creative, committed nursery staff are best able to stretch limited resources and continue to support the values of individualized care.

Staff changes in many hospitals involve reductions and reorganization. Reductions, through attrition, reassignment, or lay-offs, significantly affect both morale and consistency of care. Personnel assigned to a nursery from other units lack exposure to or training in developmentally supportive and family-centered care. Reorganization often means added responsibilities for managers, who no longer have the time to support their commitment to the developmental program. Some nurseries in the consortium have experienced a complete turnover of staff and management; some have closed.

Changes in staff-to-infant ratio are a direct result of changes in management policy. Most consortium nurseries are now caring for more infants with fewer staff. This means that staff spend their time on necessary intensive care procedures, medication, administration, and essential caregiving routines (e.g., feeding) and have little time left to devote to enhancing family-centered and developmentally supportive care. In addition to the impact on infants and families, staff who are committed to providing such care experience tension and loss of professional satisfaction when they cannot do so.

Physical relocation of a nursery—a move to a newly renovated unit or relocation with other critical care services in a "mega-unit"—may affect the implementation of developmentally supportive and family-centered care. Although a move may yield benefits, such as more space and resources for families, it is nevertheless disruptive. Some of the nursery's previously achieved developmental milestones may be lost temporarily, until a new level of equilibrium is achieved in the new unit. This is especially likely if a move involves a loss of space or a less desirable location.

The role of creative struggling

The process of creative struggling allows groups to use their resources and team attributes to identify and address barriers to progress. Creative struggling seems to be an important part of the growth of nurseries; it clarifies their vision and helps them realize their collective strength in resolving difficulties and developing new approaches. Work toward resolution of the struggle can yield new insights and progress. It is important, however, that teams articulate their goals well and incorporate concrete activities into an action plan. Otherwise, teams may have difficulty in recognizing progress toward their goals and may experience frustration and apathy, despite a consultant's best efforts to offer expertise and support.

All of the consortium nurseries have struggled to implement their goals. We have learned that when barriers seem insurmountable or external factors overwhelming, no substantial work gets done. It is acceptable—in some cases recommended—to take "time out." These "bridges of inactivity over chaotic waters" allowed nursery staff to attend to the issue at hand, and then return to work toward their goals with fresh resolve.

Nurseries progress toward their goals according to their individual time frames. The processes of creative struggling and change take more time and patience than either consultants or teams themselves expect.

In sum . . .

The Colorado consortium has grown from a few nurseries to a statewide network of NICUs, all working toward the implementation of developmentally supportive and family-centered care. The consortium experience demonstrates that commitment to change can be found not only within individual nurseries but extend to an entire statewide system as well. Unified by a common vision, entire systems can move—not easily, not steadily, but with organization, thoughtfulness, and resolve—toward changing the intensive care experience for infants, families, and professionals.

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Nursing the Premature Infant

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A mother whose infant is premature, and who hopes to nurse, is in a difficult situation. She faces looming worries about her baby's chances of survival and healthy development, and at the same time she is unlikely to be able to take any active role in his or her care. Each mother handles this overwhelming situation differently. For some, any ideas about breastfeeding fly out the window; for others, nursing becomes crucial, as the "only thing I can do for my baby."

Even when nursery policy and staff are supportive, the individual mother and her own preterm baby must struggle to become a nursing couple. Because "suck and swallow" may not become coordinated until 34 weeks gestation, many mothers must "breastfeed" a pump 24 hours per day, long before they can put their tiny baby to the breast. Once nursing begins, sessions are usually brief, and are often limited by the baby's fragility to once or twice a day. The waiting and pumping, and pumping and waiting, can seem interminable, particularly for the mothers of the smaller (<1500 grams) and younger babies. Even the mothers of larger and older babies (34-36 weeks gestation) face hurdles, such as the baby's "sleepiness." I will focus on the growth and development of the nursing relationship in preterm infants and their mothers. I will address the nutritional and technical issues involved, but will draw most heavily on detailed interviews with seven mothers of preterm infants.

Scientific issues

Is breastfeeding the premature infant a reasonable goal medically? Is breastmilk a viable source of nutrition for the preterm infant? Without fortification, the ability of term milk to produce adequate physical growth in preterm infants, particularly those with birthweights less than 1800 grams, has been questioned on the basis of randomized trials (Lucas et al., 1984; Lucas et al., 1989; Steer et al., 1992). Term milk, however, has a significantly different composition than preterm human milk (Schanler & Oh, 1980; Anderson et al., 1981; Gross et al., 1981). Although premature milk differs somewhat among mothers and changes consistently with advancing gestation, it does appear to support adequate (i.e., intrauterine) rates (Committee on Nutrition of the American Academy of Pediatrics, 1977) of growth in preterm infants who are fed their own mother's milk (Muhudhia & Musoke, 1989; Ramasethu, et al., 1993) or banked preterm milk of the same gestational age (Gross, 1983). The difference between preterm and term mothers' milk, and the fact that each is nutritionally appropriate at a different age, are remarkable reminders of the unique and crucial importance of the individual mother and her milk to her own infant.

Is premature formula "better" than premature breastmilk? Comparision trials are all short-term, and few are randomized. Faster daily gains in weight (although not in length or head circumference) can be obtained with preterm artificial formula, both as compared with, and as a supplement to, preterm mother's milk (Gross, 1983; Mercado, et al., 1990). Likewise, protein fortification of preterm breastmilk can increase infant growth rates (weight, length, and head circumference) (Carey, et al., 1987; Greer & McCormick, 1988; Kashyap, et al., 1990). These gains can exceed in utero rates, the long term benefits of which, if any, are not known. It is also not clear if fortification of preterm milk with minerals (especially calcium and phosphorus) is necessary or desirable. Although study results do not agree (Modanlu, et al., 1986;Carey, et al., 1987; Greer & McCormick, 1988), it seems likely that "approximately 50 percent of breastfed infants of less than 1800 grams birthweight [need calcium, phosphorus, and vitamin D supplementation] after hospital discharge" (Hall, et al., 1993). It appears that both fortification (addition of ingredients) and supplementation (addition of quantity, based on the mother's supply) of premature breastmilk can be individualized. Based on the available evidence, exclusive feeding of sufficient quantities of preterm breastmilk (of the same gestational age as the infant) can be nutritionally equivalent to premature formula for the preterm infant who receives careful follow-up.

Observational studies performed in neonatal intensive care unit (NICU) settings reveal that mothers can and do succeed in nursing their preterm infants, although a general consensus exists that fewer actually breastfeed than had wanted to. A survey of 327 mothers

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in a Swiss neonatal intensive care referral unit showed that at 3 months, 50 percent of mothers were completely breastfeeding and 25 percent were combining breast with bottle—rates similar to both the Swiss and the U.S. national averages for all infants (Hunkeler, et al., 1994). A Canadian study compared 55 mothers of 62 low birthweight (<2500 grams) infants with 55 mothers of 55 term infants (>38 weeks gestation and >2500 grams). Incidence rates of lactation at delivery were 58 percent for the low birthweight infants and 73 percent for the term infants, but in the long term, only 31 percent of the low birthweight infants, versus 85 percent of the term infants, were entirely breastfed (Lefebvre & Ducharme, 1989). Studies from the United States are limited in number and size, and report anecdotally higher success rates. For example, with a focused and proactive protocol, 16 of 22 mothers of premature infants intending to nurse were discharged completely breastfeeding (Stine, 1990). However, when only mothers formally "choosing" to nurse are studied, outcome results may appear more favorable than when all infants are included; the "bottlefed by choice" group often includes smaller and less mature infants who stay in hospital longer (Gunn, 1991). In countries with less neonatal intensive care availability, both low and very low birthweight infants who are, of necessity, discharged home to breastfeed can do so (Ramasethu et al., 1993). In summary, mothers who want to nurse their premature infants can be reassured that breastfeeding is an achievable goal.

Case reports

The seven mothers interviewed for this article are married, Caucasian, and middle to upper middle class, a group anecdotally representative of those seeking to nurse in this neonatal unit. Three achieved "complete" nursing, two breastfed "partially" with limited supplemental bottles, and two wanted to breastfeed but were unable to do so. Each agreed willingly to be quoted, and all spoke eagerly, reflectively, and with strong emotion. Three mothers had given birth for the first time; the others had two to four other children each. Except for one set of triplets, all were singleton births. The infants ranged in gestational age from 26 to 35 weeks, in birthweight from 700 to 2300 grams, and in chronologic age at the time of the interview from 2 months to 2 years. None had congenital malformations or required major surgery. The stories of two of these babies and mothers follow.

Pamela

Pamela, now 11 months old, was born at 28 weeks gestation, weighing 1330 grams. She required ventilation for 4 days and supplemental oxygen for 7 weeks. Mrs. G., who had bottlefed her three older children, decided to breastfeed Pamela because "it was the only thing I could do for her." Mrs. G. began pumping immediately after delivery and pumped every 3-4 hours during the day and at slightly longer intervals during the night. She had read about "kangaroo care" and "did a lot of skin-to-skin holding ...as much as I could," which she felt was very helpful to her and Pamela. She described neonatal and maternity nurses as "extremely helpful and supportive." Her husband also supported her decision to nurse, and when she would say, "I hate this pump!", he would kindly reply, "Not too much longer."

Mrs. G. finally was able to put Pamela to breast one or two times per day at 34 weeks gestational age (6 weeks after birth) but reported very little success. Pamela went home two weeks later, completely bottlefeeding, and, in addition, Mrs. G. became ill with mastitis on Pamela's first day home. But Mrs. G., who describes herself as "calm, laid back, and determined," still wanted to nurse. She obtained prompt medical treatment for her mastitis and decided (on her own) to attempt to breastfeed Pamela at each feeding, allowing half an hour for the nursing, after which she had planned to give Pamela a bottle if she did not latch on or nurse. Despite initial frustrations and difficulties, Pamela never needed a bottle and after 3-4 days, "got the idea." At 11 months of age (8 months corrected age), she now nurses three times per day and once at night, eats table food, refuses a bottle, and is beginning to use a cup. Her growth and development are normal for her uncorrected age.

Kate

Kate L., now four months old, was born at 32 weeks gestation, weighing 1100 grams, and went straight into room air to gain and grow. She is the first biologic child of Mrs. L., who said she was committed to breastfeeding prior to delivery, a desire strengthened by Kate's premature birth: "I felt it was the only thing I could do for her." Mrs. L. began pumping every 3 hours immediately after delivery. She described neonatal nurses as extremely supportive ("especially those who had been nursing moms themselves"), although occasional stepdown unit nurses joked that it would "sure be easier" to give Kate a bottle. Kate was fed by "nosetube" (gavage) initially and received only four bottles during her entire hospital stay, per Mrs. L.'s request. She was put to the breast initially once a day at 33 weeks gestational age (one week after birth) and often was gavaged while at the breast to help her associate satiety with nursing. Mrs. L. reported that at first Kate's mouth was too small to cover her nipple and that she lacked coordination and strength, although she eventually became able to latch on with a special "squeaking noise" Mrs. L. came to recognize. Kate then underwent a hernia operation two days prior to her discharge home at one month of age.

Once home, Mrs. L. attempted complete breastfeeding despite her own exhaustion and very sore nipples. Kate began to latch on and nurse, but did not gain weight. Her "phenomenally supportive" pediatrician provided a referral to a lactation consultant, who recommended changes in the position of the nipple in Kate's mouth and advised nursing regularly at two-hour intervals. No supplement was prescribed. Although Mrs. L. had one bout of mastitis, nursing appeared to be getting on track.

Two weeks later, when Kate was 39 weeks gestational age,

Mrs. L. decided to stop nursing and bottlefeed. "I decided enough was enough. It was getting too difficult, and I didn't want to be so stubborn that my baby got brain damage from not getting enough to eat. No one pushed me to stop." Mrs. L.'s husband "supported nursing completely," but he "saw me so tired all the time. Now he can help out and give bottles. I think he felt a little left out before." Kate consumed three ounces per feed by bottle. Mrs. L. had been pumping two ounces at a time. She said, "Overnight, she went from eating frantically and fussing all the time to being a baby who ate and slept." Kate began to gain weight.

Discussion

The stories of Mrs. G. and Mrs. L. raise as many questions as they answer. What permits a "successful" outcome, and what interferes? Neither of these mothers had nursed previously, and both were extremely committed to breastfeeding their babies, a decision triggered by the baby's prematurity for Mrs. G., and strengthened by it for Mrs. L. Other mothers also said they chose to breastfeed not just because breastmilk is "best" (nutritionally and immunologically), but because it was the only way to even indirectly provide for and make contact with their tiny babies. Several mothers felt that dedication and independence beyond the usual were necessary ingredients for success in nursing, and reported both feeling "different" and being treated differently by staff because of their commitment and determination. Most reported being one of many mothers pumping in the neonatal intensive care unit, but being only one of a few (or none) actually nursing in the stepdown unit. Another mother, Mrs. M., whose baby bottlefed despite her desire to nurse, commented sadly, "I really think you need to be there almost 24 hours a day... I just couldn't do that." The three mothers who had nursed previous children each volunteered that they would have quit if not for one or more prior successful nursing experiences.

Frequent pumping is essential and establishes and sustains lactation until the baby can nurse. Experts recommend initiating breast pumping shortly after delivery and pumping at least five or more times a day (some suggest 8-12 times per day) with a pumping duration exceeding 100 minutes per day to achieve adequate milk production (Hopkinson, et al., 1988; Walker, 1992). (One hundred minutes per day equals, for example, pumping both breasts simultaneously for 10 minutes roughly every 2 1/2 hours.) Advice given to (or at least perceived by) some mothers that regular (every three hours) nighttime pumping is unnecessary may contribute to lactation failure (Rogers, B., personal communication). In addition, pumping both breasts simultaneously with a heavy-duty, piston-type intermittent pressure electric pump contributes greatly to milk yield (Niefert & Seacat, 1988; Auerbach, 1990). Two mothers who had misguidedly used hand-held suction pumps at home noted their milk supplies dwindling with these devices and then increasing once they stumbled onto the solution to the problem and changed to the correct pump. The cost of home breast pump rental, estimated at $200-300, was not reimbursed by any of the several health insurers these mothers used.

Only one mother reported a "let down" sensation with pumping, yet for some, pumping became almost a substitute for nursing. Several mothers continued to pump regularly for several weeks while initiating nursing, and even concurrently with effective nursing. They recognized that they were doing "double duty," yet were unable to discontinue. When it became clear that breastfeeding was not succeeding, Mrs. M. spoke about "weaning," not in reference to her baby, but to her pump.

A significant difficulty with pumping is the lack of interaction with the infant. Rather than promoting a feeling of oneness between mother and baby, pumping focuses mothers and nurses on the quantity of breastmilk produced. Mothers commented on the arduous, time-consuming, and endless nature of the pumping that is necessary. Three who nursed successfully felt that the worst thing about pumping was not the fatigue, boredom, or occasional discomforted associated with it, or even the fact that it was time in the hospital spent **away** from the infant. Rather, for them, pumping brought worries about the baby's survival to the fore. "It (pumping) was mentally difficult. Was this baby going to survive?" (Mrs. P.) "When is (she) going to drink this milk? Will they ever be able to feed her at all?" (Mrs. S.) "Please, let my baby live to have this milk." (Mrs. R.) Mothers who are able to experience, acknowledge, and verbalize these overwhelming feelings may have a degree of personal maturity that both supports their perseverance in a crucial way and then permits them to move beyond pumping to nursing.

What about the introduction of bottles? Do they interfere with breastfeeding? Convenience, more rapid weight gain (and hence earlier discharge) are associated in most clinicians' and many mothers' minds with the use of bottles. Well aware of potential pitfalls, Mrs. L. conscientiously restricted the bottles Kate received, and yet ended up bottlefeeding, while Mrs. G.'s baby went home completely bottlefeeding, and yet was able to nurse. Is "nipple confusion" real? Do babies get "hooked" on the bottle? Experts disagree. Infants of four of the five interviewed mothers who did succeed in complete or partial nursing received frequent bottles in the nursery. The following case illustrates the extreme.

The triplets

Mrs. C. gave birth by emergency Cesarean section at 31 weeks gestation to three babies, ranging in weight from 1500 to 1800 grams. The babies were gavaged until breast and bottle were introduced. Once home, Mrs. C. nursed one baby at a time ("my special time with each one") and established a unique rotating nursing schedule. On a given day, two babies would

breastfeed completely, and one would receive only bottles. The next day, the "bottlefed" baby would become a nursing baby, and one of yesterday's "nursing" babies would have a bottle all day long. When queried about her babies' remarkable schedule, Mrs. C. laughed and said, "Yeah, I think they thought anything was better than that stomach tube!" More seriously, she wondered if introducing breast and bottle simultaneously had been helpful. She recalled that her daughter, age two when the triplets were born, had been nursed and had consistently refused a bottle.

Feeding from bottle and breast are different oral motor skills, and low birthweight babies or those of less than 33 weeks gestation who must wait to go to the breast or who are too fragile to nurse more than once or twice a day will obviously need additional oral feeds. Interim alternatives to straight gavage or bottle feeds are available and include cup feeding and both fingerfeeding and sucking on a drained breast in combination with gavage (Armstrong, 1987; Bull & Barger, 1987; Narayanan, 1989). (In fingerfeeding, the baby sucks on the mother's finger, to which is taped a tubing connected to a syringe or other device filled with milk.) However, it appears that multiple individual factors, such as the flexibility and personality styles of the mother and baby, possibly the baby's physical adeptness, and even the way bottle and breast are introduced, may be more important than the actual numbers of bottles offered. The described success of strict "no bottle" policies (Stine, 1990) may have more to do with the supportive environment that fosters such an approach than with the protocol itself. If the mother assists in the feeding plan, participates in her baby's care, uses a supplemental nursing trainer as necessary, and receives individual and conscientious support in her nursing efforts, it seems unlikely that even regular bottles will necessarily derail breastfeeding.

Barriers to breastfeeding

Initial efforts at breastfeeding were discouraging for most mothers interviewed, even though their infants were generally "healthy" prematures. Screens afforded little privacy, the lack of which, like the constant monitor noises and staff activity bothered some (especially first-time) mothers more than others. Mrs. M. exclaimed, "I just can't relax in the NICU!" She recognized that staff "checking" on her nursing efforts intended to be supportive ("Hey, how's it going?"), but she felt interrupted and then felt as if she wasn't doing well enough. Mothers described initial difficulties centering on the baby's mouth size (too small), fragility ("he had lots of [oxygen] saturation drops"), and fatiguability ("she licked and nuzzled for 10 seconds and then fell asleep").

The baby's small physical size also necessitated different holding techniques ("dancer's hold" to support the head) and extra pillows. Blow-by oxygen was not described as a significant interference. Mrs. C. commented on oxygen by nasal cannula: "Do-able but not great. It did inhibit nuzzling up, but at least I didn't have to worry about an airway!" Actually, transcutaneous oxygen saturation, minute ventilation, and breathing patterns are more optimal with breast than bottle feeding (Meier, 1988), though individual experiences may vary. Two infants had apneas with "suck and swallow" while nursing, one even after discharge. Her mother, who did nurse fully (and in fact found that her premature infant learned to latch on more quickly than her first, full-term infant), dealt with the situation calmly: "I took her off (the breast), patted her back, told her to breathe, and then she went back on."

In retrospect, several mothers felt they had expected too much in the beginning and wished they had been warned how long it would take their babies to learn to latch on and really nurse. Three reported that nursing "clicked" around 37-40 weeks gestation. Mrs. R., whose 35 week infant was ultimately able to breastfeed, said, "If only I had known from the beginning that it would all come together at 40 weeks! I would sob at each feeding . . . I was so frustrated and angry—why couldn't I nurse?"

Sources of support

Each mother noted the need for anticipatory guidance, personal support, and proficient technical help. Mothers in this sample were fortunate to have ample financial resources, available transportation, and intact, supportive families. Neonatal nurses all treated mothers' breastmilk like "pure gold" (an attitude which mothers commented on and appreciated), but nurses varied in their breastfeeding expertise. The nurses who had breastfed their own children consistently received the highest marks from mothers. A lactation consultant and the stepdown unit staff were praised by some mothers and panned by others; this points to the role of individual differences and personal factors in the interaction around as intimate an endeavor as nursing. Stepdown unit nurses typically were responsible for five or six patients; they had little time for the ongoing one-on-one assistance most nursing mothers needed. A research nurse (without clinical responsibilities) who was conducting a study on babies' physiological responses during breastfeeding sat through nursings with several mothers and was mentioned in glowing terms. Physicians were not singled out as helpful until after discharge: one community pediatrician in particular served as a significant support for three mothers. Most mothers sought resources independently and were disappointed by the paucity and poor quality of the written materials available and by the difficulty they experienced in, for instance, locating phone numbers for lactation support services they knew existed.

Although it is clearly possible to nurse a premature infant successfully, mothers must endure a significant amount of mental and physical hardship that goes well

beyond what the mother of a term infant normally encounters. Once achieved, however, a satisfactory nursing relationship appeared to give each mother an enormous boost in establishing a relationship with her child. Although this sample of mothers from a tertiary care hospital is unlikely to be representative of all mothers of premature infants, their experiences are nonetheless instructive. They are survivors, in that nursing is supported, but not proactively encouraged, in the nursery. The individual baby's and mother's personalities, abilities, and relationship appeared to be crucial determinants of outcome. Calmness, resilience, determination, good family supports, personal maturity, and a willingness to "march to the beat of a different drummer" marked the mothers in this group who were able to nurse. The breastfeeding had to be truly important to succeed, but it also seems that if nursing came to represent too much of the "premature experience," it served as a focus of anxiety, rather than of good feeling (discussion with Donna Dowling).

Turning points in the nursing relationship

There are several turning points at which the nursing relationship can either fly or fail. After the baby's birth, the mother must begin to pump regularly and frequently with a heavy-duty electric pump, and must continue to do so for one to three months. Both correct technical advice and ongoing empathic personal support are needed throughout this time. Particularly while "breastfeeding" a pump regularly, mothers may feel "locked out" of care and may feel the baby "belongs" to the nurse and not to them. They may hesitate to request private time with their infant for fear of upsetting the baby or the nursing schedule. Mrs. G. and Mrs. L.'s lactation consultant both spoke positively about "kangaroo care" (skin-to-skin contact for mother and baby), which facilitates physical closeness to the baby and lets the mother help with care in a concrete way (Whitelaw, 1990; Anderson, 1991). Few nurseries have been able to integrate this type of care into their daily routines, for a variety of reasons. However, the potential benefit of "kangaroo care" to both the mother-child relationship and to the nursing relationship seems worth exploring and has been documented in a preliminary way (Whitelaw, et al., 1988). If daily skin-to-skin contact between the mother and her infant is possible during this early phase, the mother's relationship with her infant can grow, and pumping can remain a means to an end, not become an end in itself.

A second turning point for the nursing relationship comes with putting the baby to breast and helping him or her learn to latch on and nurse. This phase seems to last at least six weeks (34 weeks to term) and demands endless patience and calm persistence from the mother. The "three steps forward, two steps backward" nature of the process is limited by the baby's physical maturity and wellbeing. Technical advice (on positioning, etc.) is helpful, but close personal support and anticipatory guidance may be even more important.

A third turning point comes when the mother attempts "complete" nursing and discontinues pumping and bottles. During and for several days preceding this process, a "hold" on major and minor medical interventions (such as medication changes, hernia operation, changes in oxygen therapy, etc.) would be helpful, so that the focus can be, if briefly, on the nursing rather than on the infant's medical condition. Cost containment, or the mother's preference, may push this transition to the home setting, though a supervised "rooming-in" space within the hospital (e.g., dormitory quarters) is workable if available.

The addition of more nursing staff, more lactation consultants, and more pro-breastfeeding protocols may or may not be helpful to mothers who are trying to nurse their premature infants. Consultants, who tend to have a short-term relationship with the mother, and nursing staff, whose professional responsibility is the infant's well-being, necessarily provide interventions which are more performance-focused and less in tune with the state of the nursing relationship. If a nursing "doula" were assigned to each hopeful nursing mother at her baby's birth (Shelley Senders, M.D., personal communication) longitudinal, individualized personal support would be available during these critical times.

The concept of a nursing "doula" is not new or original; the La Leche League has used this approach with success. Perhaps there are neonatal nurses who have nursed their own children who would have an interest in this role, which involves supporting a person (the mother) and a relationship (the nursing). Performance of this skilled and time-consuming job would need to be reimbursed, and separated in time and space from other professional duties (such as infant care), possibly as part of a staff nursing position. Such a support person needs to know not only breastfeeding in a "hands-on" way, but also premature infants; she "practically needs to be a therapist."

The emotional vulnerability of any postpartum mother is compounded for the mothers of premature infants, whether or not they want to nurse, by the stress of premature labor and delivery and by ongoing reality worries about the baby's condition. Ideally, sorting out, clarifying, and discussing feelings about the baby, the pregnancy and delivery, and the nursing; providing technical support and advice; and sitting with the mother through multiple nursings would all be part and parcel of the nursing doula position. Although some may feel this simply describes the job of a good lactation consultant, few neonatal intensive care units have the resources to fund enough consultants familiar with prematures for the number of mothers hoping to nurse, given the amount of time required to forge and maintain a relationship with each.

Nursing is a relationship, and its support may best be

accomplished through a relationship. Thus, longitudinal interactive guidance to mothers may offer an advantage over protocols based on specific interventions. The potential benefits of "kangaroo care" in promoting the mother-child relationship (and hence the nursing relationship) seem under-appreciated. Breastfeeding even a healthy premature infant is very difficult, however, and may not be a reasonable goal for many, or even most mothers. If those who do hope to nurse are given guidance that brings them closer to their infants, a great deal will have been achieved. A successful nursing relationship is a significant achievement, and may herald a positive and satisfying relationship after an extremely difficult and stressful beginning.

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Call for Manuscripts

Clinical Child Psychology and Psychiatry, which will begin publication in January, 1996, will publish papers between 5000 and 10,000 words in length, as well as short papers, annotations, commentaries, debates, book reviews, and correspondence. Correspondence should be sent to Dr. Bryan Lask, Department of Psychological Medicine, Great Ormond Street Hospital, Great Ormond Street, London WC1N 3JH, UK, tel: +44(0) 171 829 8679; fax: +44(0) 171 829 8657. Books for review should be sent to Bernadette Wren, Book Review Editor, 177 Brooke Road, London E5 8AB, UK.

Early Intervention and the NICU Health Professional: An Interdisciplinary Training Model

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Seeing my baby hooked up to all those tubes and wires, I didn't want to touch her. But the intensive care staff helped and supported us while my baby was there. When we finally took her home we felt like new parents at last. I thought that all of that medical and hospital time was over. But at her six month follow-up, we were told she would need physical therapy.

The most discouraging thing for me was that one of my twins who was born prematurely did not do as well as the other twin. When he was born we were not even sure if he would make it. Well they both came home but not at the same time, and he continued to be slower than his brother. At 18 months his brother said words and walked but he didn't. So his doctor put us in touch with an early intervention program where he's now enrolled. No one at the hospital told us this might happen.

Every year over 200,000 premature infants are born in the United States (National Center for Health Statistics, 1990). With advances in neonatal care, the survival rate of these infants has dramatically increased. Moreover, infants of 23 weeks gestational age or weighing less than 750 grams are being kept alive routinely. These very fragile babies are at risk for developmental delay. Approximately half of very early, low birthweight infants will require early intervention services, including long periods of specialized hospital care in neonatal intensive care units (NICUs) (Bruder & Cole, 1991). As survival rates have increased, so too has the incidence of chronic impairments, physical disabilities and developmental disorders (Long, Artis, & Dobbins, 1993; Hack & Fanaroff, 1993). This serious situation requires our best efforts in a rapidly changing context.

The increased survival rate of premature infants has focussed our attention on the need for and types of services we provide for these infants and their families. Are we doing enough for them? Are we engaging the family early enough? Are we providing appropriate interdisciplinary early intervention? Until recently, early intervention for infants with disabilities and their families began sometime after discharge from the NICU. NICU health professionals often tend to view discharge as a successful end to hospitalization. But families often view discharge differently. For many of them, discharge will in fact be the beginning of a long process that involves ongoing medical and therapy services as well as a continuing search for early intervention services (Bruder & Walker, 1990; Sabbeth, 1984).

The family experience in the NICU

I thought having a baby in the hospital for three months was the hardest thing I would ever experience. I was told that there might be some problems because she was so tiny, but I was unprepared when she was diagnosed as having cerebral palsy.

The birth of a premature, fragile infant is stressful for the family in many ways (Hughes, McCollum, Sheftel, & Sanchez, 1994). Not only is the birth unexpected, but the infant's potential medical crisis and extended hospitalization, coupled with the overwhelming NICU environment, may take a toll on families' energies and resources at a time when they most need them (Wyly & Allen, 1990). Furthermore, family routines are disrupted as family members spend time visiting the infant. Because extended family members and friends may not know what to say or do in response to a premature birth, valuable social support may not be available to parents.

Parents often feel out of control while others care for their baby in the NICU. Their parental role as primary caregivers is often taken over by professional staff. NICUs that involve families in decisions and encourage family members to participate in non-medical caregiving procedures and developmentally supportive comforting measures for their infant enable and empower parents in their role as caregivers.

Infants in the NICU who are acutely ill or at developmental risk are likely to require early intervention services in the NICU and after discharge. But when the system of care is fragmented and disorganized, or simply not available, additional stress is placed on families who face difficult decisions about obtaining services for a child with an identified disability or at developmental risk. Clinicians have suggested that this stress jeopardizes the nature of the current and future parent-infant interactions (Affleck & Tennen, 1991).

Even when infants who graduate from the NICU are physically and developmentally normal, the transition from hospital to home can be problematic for families (Pearl, Brown, & Myers, 1990).

When an infant is discharged from a NICU, parents report feeling helpless and alone (Ensher & Clark, 1994; Hanline & Deppe, 1990). When their infant is home, parents report that they lack confidence in their parenting skills for their premature infant (Sheikh, O'Brien, & McCluskey-Fawcett, 1993). In addition, parents may often lack definitive information about their infant's future.

Families who expect that once their infant is home, life will be normal are often shocked and dismayed about the infant's ongoing medical and developmental problems. In fact, some infants may need a variety of services that continue well into the elementary school years or beyond (Blackburn, 1995).

To meet the needs of families with preterm infants with developmental disabilities or who are at risk for developmental delays, NICU health professionals and early interventionists need to work collaboratively. The challenge is to provide family-centered early intervention services in the NICU, through discharge, and in transition to community early intervention services.

IDEA and NICU infants born at developmental risk

The Individuals with Disabilities Education Act (IDEA, Part H) responded in part to the situation by making hospitalized infants and their families eligible for family-centered developmental services (Dobbins, Bohlig, & Sutphen, 1994; Krehbiel, Munsick-Bruno, & Lowe 1991). This action was consistent with current trends in early intervention, which identify hospitals as important sites for early intervention services and family support (Flynn & McCollum, 1989; Gilkerson, 1990; O'Brien & Dale, 1994).

While general consensus on "best practice" emphasizes parent-professional collaboration and program design that recognizes the family as the constant in an infant's life, (Shelton, Jeppson, & Johnson, 1987), the reality of practice is another matter. In fact, we are a long way from providing a seamless system of family-centered early intervention in the NICU, at discharge, and through transition to community early intervention services.

Despite federal legislation (IDEA, Part H) that identifies the hospital as a site for family-centered early intervention services, this focus has only recently become a training priority for NICU health professionals. NICU training traditionally has focused on technology, new medical procedures, and medications rather than on meeting family needs. That NICU staff are now looking for ways to provide systematic training on implementing early intervention services within a family-centered neonatal care model represents a true paradigm shift.

Because early intervention professionals are now assuming a more central role in preparing families and premature infants for their discharge from the NICU and in helping families find and use early intervention services (Thorp & McCollum, 1988), they need to work more closely with NICU health professionals to deliver family-centered early interventions for at-risk infants and their families and facilitate transition to community early intervention programs (DeSocio & Ensher, 1986; Gilkerson, Gorski, & Panitz, 1990; Thurman, 1991; Zeanah & Jones, 1982). Early intervention professionals need to learn about premature infant development, the outcome of medical stressors on the infant, common problems of infants in the NICU, procedures and equipment used in neonatal intensive care settings, and developmental problems specific to premature infants. They need to increase their awareness of the impact of the premature birth on the family system and the long term outcomes on both family and infant. Finally, in order to develop an Individualized Family Service Plan (IFSP) as mandated by Part H, the infant interventionist needs to be able to identify ways to help families regain control over their lives while supporting them in accessing professional services (Cooper & Kennedy 1989).

Evolution of the NICU Training Project

Since 1985, with support from the Office of Special Education and Rehabilitative Services in the Department of Education (OSERS), we have developed, validated, and disseminated the NICU Training Model. Originally, we designed this model for neonatal nurses and other NICU and pediatric health professionals who serve infants with disabilities in neonatal intensive care units; we focused our early efforts on the infant and the NICU nurse as caregiver.

In the next stage of our model development, we moved toward a stronger emphasis on the family and parent-professional relationships. We began to include parents of premature infants in our training workshops. As part of that effort, St. Luke's Hospital and Western Hills Early Intervention Center of Sioux City, Iowa asked us to offer a training workshop whose participants would be drawn from the hospital's NICU and the Western Hills early intervention staff of infant teachers, physical, speech and occupational therapists, social workers, and a parent advocate. While this mix was outside our original program's design, the idea was appealing. We tried it.

We found that NICU nurses, teachers, and other early intervention professionals were enthusiastic about interdisciplinary training. The opportunity to learn from one another and describe the unique skills each group uses was enlightening. Most important, workshop participants felt that the training would help them provide improved services for infants and toddlers with disabilities.

We were excited about the enthusiastic response and the outcomes from the Sioux City training. So in 1991, when we received a similar request from Buffalo, New York for a training workshop including a combination of NICU-based related service personnel and early

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intervention professionals, we tried the adapted NICU Training Model again.

Our follow-up of these training workshops showed that both NICU and early intervention personnel used what they had learned in the training. NICU professionals told us they gained an appreciation of the importance of family-centered NICU care and the need to individualize family services starting in the NICU. The early interventionists learned what infants and families experience in the NICU and better understood their special needs. At the training's conclusion both groups developed (and later implemented) a formal plan for sharing information and maintaining contact.

We searched the literature and talked with colleagues around the country but found no comparable training program. We did, however, find that others were aware of the need we first recognized in Sioux City. Cooper and Kennedy (1989) wrote:

Advances in neonatal intensive care have dramatically increased the survival rate of infants born prematurely or with medical complications. Figures show that the number of neonatal intensive care units (NICUs) in the United States increased from 448 to 594 in 1985 (Hospital Statistics, 1987). Increases in infant survival rates, coupled with the enactment of (P.L.) 99-457, have created a necessity for professionals involved with infant service delivery to have up-to-date knowledge concerning neonatal intensive care...Consequently, the infant interventionist must be well acquainted with the treatment approaches utilized in the NICU.

Beginning in 1992, again with funding from OSERS, we modified our initial model by including hospital-based and community-based early interventionists in our training population. Whenever possible, parents of NICU infants who require early intervention services were also included as training participants. We continued our family-centered focus and added information about Part H, IFSPs, discharge planning, and transition to community-based services to our curriculum. For the past three years, we have refined the model and tested it with NICU and early intervention professionals at 10 hospitals throughout the country.

The results have been overwhelmingly positive. Not only did the 200 participants positively evaluate the training model but our follow-up data showed that significant changes resulted from the training. The following are several typical participant comments about our joint training design:

- It was very interesting to "try on" others' shoes.
- Continue to "mix" professions; it was very effective.
- Keep using small groups, role plays, case studies, videos, and combining NICU professionals and educators.

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• The group sharing enhanced the realness and openness in dealing with family issues.

The NICU training model

The NICU training model addresses: 1) team collaboration for delivery of family-centered neonatal care services; 2) the high-risk infant experience in the NICU and through transition; and 3) the family experience in the NICU and through transition to community early intervention services. Specifically, the training model is designed to train NICU health professionals and early interventionists to:

- Work collaboratively as a team with families and infants;
- Use individualized assessments of infants and families;
- Employ developmentally supportive care with infants;
- Assist families in supportive infant interventions;
- Recognize and appropriately respond to parent emotional states;
- Create supportive environments for infants and families in the NICU and beyond;
- Implement family-centered neonatal care;
- Provide continuity of intervention services from hospital to home;
- Develop services consistent with Part H, including IFSPs and transition planning.

The training is designed to bring about cognitive, affective, and behavioral change. Our past training experience has shown us that the training model must have a strong philosophical base, employ interactive learning methods, and teach participants the curriculum content.

Participants are selected based on experience, commitment to family-centered neonatal care, and their agreement to facilitate family-centered care practice in support of families with infants at risk for developmental disabilities. The participant mix varies, depending on the site and area needs. A typical group of participants might include neonatal nurses, neonatologists, physical therapists, occupational therapists, respiratory therapists, early interventionists, hospital-based follow-up personnel, social workers, psychologists, speech-language pathologists, and parents of NICU infants. Because of the interactive nature of the training, we limit groups to 25 participants.

We choose hospital training sites based on the population they serve, their commitment to implement Part H of IDEA within the context of family-centered care, their links to early intervention services, and their willingness to incorporate the elements of the NICU Training Model into the institution's ongoing inservice training program.

Training is conducted over two days and involves adult learning processes, small group designs, video analyses, demonstrations, simulations, and role plays. We use follow-u- evaluations with participants and families to assess how well training is translated into practice.

Training consists of 1) discussion of the content material studied by participants prior to training; 2) providing additional content information to participants; 3) demonstrations of developmental care practices with infants, effective communication strategies, and individualized assessments; 4) role-play and case study analyses of professional-professional communication, parent-professional communication and family interventions; 5) focus group discussion on team building and ways to implement family-centered care; 6) structuring intervention strategies; 7) analyses of videotaped infant behaviors and states, professional-parent communication, and infant interventions; 8) small group problem solving; 9) practice in specific intervention techniques in the NICU, writing IFSP's in the NICU, and drafting discharge/transition plans; and 10) using problem solving and communication in collaborative team efforts.

The training is designed to maximize participants' learning and to facilitate team collaboration for family-centered care. Thus the two days of training are highly interactive and afford opportunities for NICU and early intervention professionals to learn from one another. Several examples of training activities will illustrate how we facilitate this process.

Early in the training workshop, the NICU health professionals form a circle to discuss some of the work stressors associated with caring for premature infants and their families in the NICU, the stressors' impact on them, and ways they address the problems associated with the stressors. While they talk, the early interventionists listen from an outer circle. This is called a fishbowl design. The same type of group discussion is then conducted with the early intervention group in the inner circle. Although the fishbowl lasts only 30 minutes, it allows each professional group to quickly learn what the other does, as well as to identify some pertinent issues and problem-solving strategies concerned with providing family-centered early intervention services for infants and their families.

Effective communication is a key theme throughout the training. Families have identified communication problems with professionals as a potential barrier to successful implementation of family-centered neonatal early intervention. We have written role plays based on real family-professional situations. These scenarios are then given to small groups of participants, who are asked to select players and plan how they will play the scene. **One role play depicts parents visiting their infant in the NICU where they are told that their baby is ready to go home later that day. The parents do not feel ready for the discharge, but a NICU staff member assures them that they are. In another role play, a parent whose infant has been discharged from the NICU**

is visited in her home by a hospital-based early intervention follow-up team who inform her that her infant will need early intervention services. The mother insists that her baby is fine, since he was well enough to be discharged from the NICU.

Role plays are used as a vehicle for training participants to "feel" what it like to be a parent who is negotiating the system. Since each role play contains a conflict situation, they also offer participants the opportunity to practice ways to deal with conflicts as well as support families. While the role plays are fun and serve to energize the group, the discussion that follows touches on many salient issues concerned with alternate ways of managing parent-professional and professional-professional communication problems, interdisciplinary teamwork, and sensitivity to families. Interestingly, at the outset of the workshop, participants will often remark that they don't like role playing, but at the workshop's conclusion, they will identify role plays as one of the most effective training tools in the workshop.

Another training design used to link the expertise of NICU and early intervention professionals is a small group task of drafting an individualized developmental care plan for a hospitalized infant (Cole, Begish-Duddy, Judas, & Jorgensen, 1990).

The one-page plan contains several simple completion statements about the infant —e.g., My name is _____. I can_____. I get stressed by____. You can promote my well-being by_____. Each group completes the plan, based on a description of the hospitalized infant presented by a group member who is a NICU health professional. Each group then presents its plan, followed by a large-group discussion directed at ways to involve families in writing the plan, update it as the infant progresses, incorporate it into an IFSP, and use it as a communication tool with other professionals.

Towards the end of the training workshop, a focus group is used to address the question, "What do we have to change in our practice to reach a seamless system of service delivery for families and infants?" It is in this small group format that NICU health professionals, hospital-based and community-based early interventionists, and parents identify what changes need to be implemented in their programs and how to do it. Initial plans for collaborative teamwork are identified at the workshop's conclusion.

Effecting change

The real difficulty in changing the course of any enterprise lies not in developing new ideas but escaping from old ones.
John Maynard Keynes

The goal of training is change—shifting paradigms, breaking old habits, and trying new behaviors. A two-day joint training experience provides opportunities for NICU health professionals and early interventionists to share their experiences and identify ways to change their current practices in order to achieve greater collaboration. During the training process we emphasize that for change to occur, training participants must not only work individually or in teams to model the desired behaviors in their own work settings, but also work systematically as a group to implement programmatic changes. Further, they must share the training content with others in the NICU or early intervention program to promote ownership of the ideas and facilitate support for change. Follow-up is a key to successful training.

What changes do training participants achieve? In our follow-up evaluations, participants tell us that they have a greater awareness and sensitivity to the needs of NICU infants and their families. A parent of premature infant who is also a special education teacher commented:

Being a parent who survived the NICU experience, I look back and realize how much more could have been done to comfort my baby and alleviate the stress put upon our family. As a special education infant teacher, I found the discussion of strategies for helping families cope with their experiences invaluable in dealing with the emotional baggage parents often carry for years after their NICU experiences. The NICU Training Project has reminded me to keep our interventions baby-led and family-focused. (S. Schultz, personal communication, December, 1991)

Participants report specific changes in implementing family-centered early intervention, staff education, and linking the resources and expertise of NICU and early intervention professionals. The changes made reflect the specific needs of the participants from each site.
NICU staff who participated in training have at the various sites have:

- created a developmental task force
- formed a Family-Centered Care team
- provided educational seminars/inservices on developmental care, family support and early intervention
- established a Family Advisory Council
- written a family support grant
- modeled and mentored appropriate developmental interventions with staff and families
- included physical and occupational therapists as team members in planning developmental care
- established a staff informational network e.g, bulletin boards, newsletters, videos
- established developmental rounds that include early interventionists
- structured a more welcoming climate for families in the NICU.

Early intervention training participants report the following post-training activities:

- hosted one-day practica in the EI program for NICU staff
- early intervention staff spent a day in the NICU
- conducted inservices with parents of premature

infants as speakers or family needs

- established a parent resource library to assist transition from the NICU to early intervention
- conducted in-service trainings in the NICU on long-term developmental problems, assessment, and family experience in transition from the NICU
- identified liaisons between community early intervention and the NICU
- drafted transition plans with NICU staff.

Conclusion

As service providers and families look for ways to improve the life circumstances of the high-risk infant in the NICU, systematic efforts are being made to train personnel cooperatively to meet the challenges of this new field (VandenBerg, 1987). A comprehensive, coordinated multidisciplinary, interagency approach to serving infants and their families requires cooperation between hospitals and early intervention services.

For the past 10 years, we have developed and adapted our training program to meet the changing needs of professionals who work with premature infants and their families. The training we have conducted in sites across the country has led to numerous changes in both NICUs and early intervention programs. While developmental care in the NICU and family-centered early intervention in the community are by no means universally available, we do see a commitment to better serve fragile babies and their families.

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Letters to the Editor:

For the past four years, I have coordinated an early intervention program in rural Alaska. The program covers an area the size of several states—40-plus communities spread over the interior of Alaska. Only a small portion of these communities is accessed by a system of roads; the rest is accessed only by air or boat. The challenges faced by all rural providers are compounded by extreme weather, incredible distances, multiple cultures, lack of "modern" conveniences, and a critical shortage of funds. Weather can range from zero to 80 degrees below zero in the winter, with snow from September to May. Since most travel is done in small planes (two to 13 seats) to villages without control towers or landing lights, it becomes a major undertaking to make monthly visits to families. Communities range from one- to four-hours' travel time by air each way, to eight hours by car on the road system. Planes are unheated in the winter; roads must be plowed continuously in the winter and are usually under construction in the summer. People with medical emergencies are usually flown from their village to Fairbanks, with the time between placing the call for medevac to arrival in Fairbanks ranging from four to 12 hours—weather permitting.

The families we serve are from varied ethnic and socio-economic backgrounds, including Athabaskan Indian (speaking several dialects), Inupit and Yupik Eskimo, Caucasian, and African-American. A majority of the families live a subsistence lifestyle (dependent on trapping, hunting, and gathering) and receive some assistance either from the state or tribal government. Homes are usually without running water or sewage disposal systems. All communities have electricity and phone service, but both are erratic at times.

These factors all combine to make our service delivery different from programs described in the April/May, 1995 issue of *Zero to Three* on working with infants, toddlers, and their families in rural areas and small towns. The article by Sue Forest on challenges and strategies is probably accurate with respect to typical rural areas; however, it does not address the challenges faced in remote rural areas such as Alaska. Home visits here are, unfortunately, scheduled every four to six weeks with families, due to the enormous distances and costs of travel. Teleconferencing with families is limited, since not all families have phones or easy access to phones. In addition, cultural differences make non-face-to-face contacts limited in value, since several cultures rely on body language to complete communication. Connecting other professionals to rural remote areas involves extra challenges, for several reasons. Therapists who are willing to give up valuable (and expensive) treatment time in town to journey to remote sites to do evaluations and/or therapy are extremely rare. A critical shortage of physical, occupational, and speech therapists means that families are fortunate if a therapist accompanies the early interventionist once or twice a year. Alaska has a statewide travel team of therapists who assist remote programs, but they are so overloaded that two trips to each program are the maximum available.

The early interventionist becomes the main point of contact for families, providing support, guidance, activities, contact with the occasional therapist, and volumes of information on every topic from toilet training to specific therapy exercises. We work as closely with other professionals as possible, but programs must be designed which the family or other village supports can follow with success. Trips to town for therapy sessions are close to impossible for most families, due to distance, weather, and cost. Professional isolation is the greatest drawback to serving this area; we can often connect only by phone, except for one convention per year. Ideas are shared through a support network of others who are doing the same type of service with equal challenges. We read journals such as *Zero to Three* to keep current with new ideas and strategies in the field.

Providing early intervention services to families in remote rural areas increases the challenges, but it also allows us to participate in family life in ways which other providers seldom achieve. It is not unusual for our families to include us in village gatherings to celebrate birthdays, anniversaries, funerals, or other special occasions. We have been invited to fish camps, boat rides, snow machine treks, and carnivals in the spring. We are given unique glimpses into a pattern of life that is very different from our past experiences or training, since most providers are from the lower 48.

Veleta Murphy
Coordinator/Early Intervention Specialist
Infant Learning Program
Tanana Chiefs Conference, Inc.
Fairbanks, Alaska

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I really enjoyed the latest issue of *Zero to Three* and read it with a personal interest. I have two daughters; my youngest was born with spina bifida and hydrocephalus. I also work as an early interventionist. In 1990 we moved to North Central Washington from Portland, Oregon. We lived there till July, '94, when we moved to Southeastern Minnesota. I am very interested in policy implementation and service delivery in rural areas. I read the articles eagerly and could relate to much of what the authors were describing.

After moving several times and becoming interested in "rural living," I wanted to know what the definition of a rural area was. B.D. Rios states (1988) that developing a definition has been a conceptual problem for educators, legislators, demographers, sociologists, and others for some time. Even though much of the midwest is rural (I grew up on a farm in Wisconsin), I started making a distinction between rural and remote/rural. In Sue Forest's article, the term remote/rural is used in the first sentence. Some of the differences as I see them involve access to local services. While living in North Central Washington I had to drive many hours over mountain passes to get to my daughter's medical specialists. We had much the same issues as were mentioned in the articles: difficulties in recruiting and retaining qualified personnel, no public transportation, scarcity of services or having to travel great distances to obtain them, few resources and supports. At the time we lived there, we had a wonderful early intervention program. Our birth-to-three program was home-based; one of the components of our childfind was "taking our show on the road." Our county was very large, and many families did not have transportation. Our staff traveled to day care centers and clinics and did screenings. We also followed families through the mail with our Follow Up Network (FUN). This program would have never been available in this remote/rural area if a few had not had the vision or dedication to make it happen. This is also apparent in reading the articles in the April/May issue of *Zero to Three*.

The most important factor in services or policy implementation in any area is people. The visions, the dedication, and attitudes. This has always been my experience, as both parent and professional. The beliefs, dreams, and dedication of people make services possible. This is true at both state and local levels. I truly appreciate those people—professionally, because I am able to work in the profession I truly love, and personally, because they have made a difference in my daughter's life.

Teresa Wong
Winona, Minnesota

Rios, B.D. (1988). "Rural": A Concept beyond Definition? (Report No. EDO-RC-88-09). Washington, DC: Office of Educational Research and Improvement (ERIC Document Reproduction Service No. ED 296820).

Publications

Developmental Interventions: Premature Infants and Their Families (1995)-M. Virginia Wyly (Singular Publishing Group, Inc., 4284 41st Street, San Diego, CA 92105-1197) $29.95.

This volume, focusing on what can be done to enhance the development of high-risk preterm neonates, is designed to demystify the "earliest of interventions." Drawing on empirical research, theory, and application, Wyly and colleagues Jack Allen and Janet Wilson present case histories, suggestions for neonatal intensive care unit environmental interventions, and specific comforting techniques and strategies for caregiver and family coping. Techniques outlined include multimodal sensory stimulation, state modulation, neuromotor interventions, and stress alleviation. Family issues are addressed in chapters on family-preterm infant interactions, family reactions to premature birth, and family-centered care in the NICU.

Low Birth Weight (*The Future of Children, Vol. 5, Number 1, Spring, 1995*)-Richard E. Behrman, Editor (The David and Lucile Packard Foundation, 300 Second Street, Suite 102, Los Altos, California 94022) Free by request.

This issue of *The Future of Children* focuses on the "seemingly intractable" problem of preventing death and disability in infants as a result of being born too soon at low birth weight. The 14 essays in this volume summarize knowledge and experience about the causes of low birth weight, prevention efforts, and the care of babies born prematurely. Jeffrey Horbar and Jerold Lucey review the effectiveness of technologies used as part of neonatal intensive care and discuss several new approaches to evaluating neonatal technology. Marie McCormick and Douglas Richardson discuss the development of regionalized NICU services and the current trends toward deregionalization. Maureen Hack, Nancy Klein, and H. Gerry Taylor provide a critical review of the physical, neurosensory, intelligence, behavioral, school performance, and health outcomes of very low birth weight infants. Jon Tyson analyzes ethical questions faced by health care providers, administrators, and parents who care for the extremely low birth weight infant.

Neonatal Nursing (1994)-Doreen Crawford and Maryke Morris, editors (Chapman & Hall, distributed in the U.S. by Singular Publishing Group, Inc., 4284 41st Street, San Diego, CA 92105-1197) $42.99.

Written by senior clinical nurses at the Neonatal Nursing Unit, Leicester Royal Infirmary, UK, for neonatal and pediatric nurses, midwives, and their students, this text focuses on nursing actions and responsibilities in care of the sick newborn, providing relevant research findings, pathology, anatomy, physiology, and clinical applications. In an effort to offer a holistic overview of

infant care, the volume addresses ethics, continuing care in the community, intranatal care, statistics, pharmokinetics, and explanations of terminology.

The Best Intentions: Unintended Pregnancy and the Well-Being of Children and Families (1995)-Sarah S. Brown and Leon Eisenberg, editors (National Academy Press, 2101 Constitution Avenue, N.W., Lockbox 285, Washington, DC 20055) $29.95. Limited supply of copies of Summary available free of charge from Division of Health Promotion and Disease Prevention, Institute of Medicine, 2101 Constitution Avenue, N. W., Washington, DC 20418.

Experts estimate that 57 percent of all U.S. pregnancies are unintended, either mistimed or unwanted altogether. Not just a problem of teenagers or unmarried, poor, or minority women, unintended pregnancy affects all segments of society. In this report, the 13-member Committee on Unintended Pregnancy of the Institute of Medicine describes the number and complexity of factors resulting in unintended pregnancy and its consequences. The committee urges that the nation adopt a new social norm: That all pregnancies should be intended—that is, they should be consciously and clearly desired at the time of conception. They advocate a campaign to reduce unintended pregnancy, aiming: 1) to improve knowledge about contraception and reproductive health; 2) increase access to contraception; 3) explicitly address the major roles that feelings, attitudes, and motivation play in using contraception and avoiding unintended pregnancy; 4) develop and scrupulously evaluate a variety of local programs to reduce unintended pregnancy; and 5) stimulate research to a) develop new contraceptive methods for both women and men; b) answer important questions about how best to organize contraceptive services; and c) understand more fully the determinants and antecedents of unintended pregnancy.

Cost, Quality, and Child Outcomes in Child Care Centers, Public Report (1995)-Cost, Quality & Child Outcomes Study Team (Cost and Quality Study, Campus Box 159, P.O. Box 173364, University of Colorado at Denver, Denver CO 80217-3364) Executive Summary (20 pages) $8.00; Public Report (85 pages) $15.00; Technical Report (400 pages) $40.00.

In 1993 and 1994, researchers from the University of Colorado at Denver, the University of California at Los Angeles, the University of North Carolina at Chapel Hill, and Yale University collected and analyzed data from 401 child care centers and 826 preschool-aged children attending a subsample of these centers. Study findings, reported in the general media in January, 1995 and elaborated in the study's Public Report, revealed that child care at most centers in the United States is poor to mediocre, with care in 40 percent of the infant and toddler rooms observed to endanger children's health and safety. Only one in 12 infant and toddler rooms were judged to be providing developmentally appropriate care. The quality of child care was primarily related to higher staff-to-child ratios, staff education, and administrators' experience. In addition, teachers' wages, their education and specialized training were the most important characteristics that distinguish poor, mediocre, and good-quality centers. The study's Technical Report, meant as a reference work for professionals in the field of early childhood education, economists, and researchers, describes study objectives and research questions, offers descriptive comparisons of the centers, analyzes results, and presents major findings and recommendations; 100 tables are included.

Two Generation Programs for Families in Poverty: A New Intervention Strategy (1995)-Sheila Smith, Editor (Ablex Publishing Corporation, 355 Chestnut Street, Norwood, New Jersey 07648) $24.50.

This volume, part of the Advances in Applied Developmental Psychology series, is designed to provide a comprehensive understanding of a two-generation intervention strategy, an approach that integrates two kinds of family supports: 1) self-sufficiency services designed to improve the parent's education level, vocational skills, and employment status; and 2) child development services that may include preventive health care, parenting education, and high quality child care or early childhood education. Chapters examine the theory underlying this approach, the challenge and opportunities practitioners face in attempting to implement two-generation programs, and the complexity and importance of research that can determine the effectiveness of specific models. Contributors include, among others, Byron Egeland, Sarah M. Greene, Robert Halpern, Toby Herr, Wade F. Horn, Faith Lamb Parker, Chaya Piotrkowski, Jane Quint, Craig T. Ramey, Sharon Landesman Ramey, Gloria G. Rodriguez, Sheila Smith, and Martha Zaslow.

Preparing Collaborative Leaders: A Facilitator's Guide (1994)-Wendy Russell (The Institute for Educational Leadership, Inc., 1001 Connecticut Avenue, N.W., Suite 310, Washington, D.C. 20036) $95.00.

This guide is designed to offer support for the training and development of leaders who are open to thinking about and solving problems in new and collaborative ways. Activities and exercises in the Guide are designed to tap participants' prior knowledge first, then challenge (and perhaps replace) their views and operating assumptions. It encourages participants to examine opportunities for change within their own organization. Fifteen units are designed to: 1) draw on each participant's work experience; 2) engage learners through a variety of training approaches; 3) build on group process and team development skills; and 4) use current research and resources on collaboration and leadership. Assuming a 12-month program to train collaborative leaders, the guide outlines meetings in three phases, "getting together," "mastering the essentials," and "building change" (with a specific collaborative effort in mind.)

Videotapes

Caring for Premature Babies (1994). Produced by PAD/WPE Productions and distributed by Films for the Humanities & Sciences, PO Box 2053, Princeton, NJ 08543-2053, tel: 800/257-5126. 30 min. $149.

In a news report format, this video explores the risks for pre-term labor, the possible steps to postpone it, and the problems of the premature infant. Foremost among the infant's problems are underdeveloped lungs, but prematurity affects all body systems and puts the infant at risk for learning disabilities, cerebral palsy, and eye and ear impairment. The program covers some of the tools now available to save young lives—tools that can also cause damage. Some of the ethical issues involved in helping very low birth-weight babies to survive are discussed.

YEAR ONE (1993). Produced at The George Washington University and distributed by Learner Managed Designs, PO Box 3067, Lawrence, KS 66046, tel: (913) 842-9088.

The YEAR ONE materials were designed as a resource for health and education professionals to help them provide an effective and responsive continuum of care for infants with special needs and their families. Each module contains a videotape and a resource guide.

The Family Experience. 45 min. $249. This tape, in two parts, documents the emotional experiences of families whose infants are at risk for developmental disabilities due to prematurity or other conditions. Part I addresses the experiences of families from pregnancy through birth and early months of life and the decisions facing them when their infant requires a lengthy hospitalization. The role of professionals in assisting families with their decisions is examined. Part II looks at hospital practices that support families in taking over the care of their infants and integrating them into their family life.

The Neonatal Experience. 45 min. $249. Designed to be used in preservice or inservice training of service providers in community-based early intervention programs, this two-part video illustrates the major medical complications of infants who are premature or at risk for developmental disabilities. Topics include NICU terminology; systemic conditions such as jaundice, respiratory conditions, cardiac conditions, and central nervous system concerns; deficits of vision and hearing;and possible complications associated with feeding and growth.

The Community Experience. 30 min. $198. When an infant born prematurely or at risk for disabilities is medically stable and ready for hospital discharge, the need for ongoing services remains. This video presents information on developmental outcomes, assessments and community resources that will enable pediatricians or caregivers to counsel parents and make informed and appropriate referrals. Interviews with physicians, therapists, developmental specialists, educational professionals and parents are featured.

The NICU and Pediatric Video Series (1990). Produced by Judith L. Porkorny, Ph.D. at the Georgetown University Child Development Center and the Georgetown University Division of Neonatology and distributed by Polymorph Films, 118 South Street, Boston, MA 02111, tel:800/ 370-3456.

These videos translate research on development of hospitalized preemies, infants and older children into specific ways of promoting emotional and physical health. Study guides, bibliographies and pre/post tests are included.

The NICU Video Series includes the following:

Preemie Development: An Overview. 14 min. $175. Provides a comprehensive review of the general sequence of preemie development - early preemie, developing preemie and older preemie. The various stages of preemie development are outlined including the behavioral states, physiologic and motor responses and attentional reactions of preemies.

The Preemie and the NICU Environment. 16 min. $175. Explains the variety of ways in which preemies react to stress and illustrates typical self-comforting behaviors. Also described are ways in which staff can reduce excessive stimulation that all too frequently occurs in the NICU and how they can help facilitate a preemie's self-comforting.

Positioning and Handling the High Risk Infant. 15 min. $175. Explains the importance of proper positioning and handling and illustrates how positioning and handling can be used to normalize a preemie's muscle tone and movement patterns.

The Growing Preemie. 12 min. $175. As the preemie responds to care and develops in the NICU, ways of promoting sleep, encouraging alert times, reducing fussiness and facilitating feeding in the growing preemie are both explained and demonstrated.

Helping Families in the Special Care Nursery. 14 min. $175. Reassuring parents and encouraging their involvement in the care of their infant is an important part of a NICU nurse's role. This video instructs nurses how to identify parent's feelings and coping strategies and ways in which staff can help parents to adjust to the NICU experience.

Parenting the Acutely Ill Infant. 14 min. $175. This video is intended for showing to parents whose infants have recently been admitted to the NICU as a way of facilitating their adjustment to this potentially frightening environment. Explaining what happens in the NICU and presenting common feelings helps parents to better

understand and care for their infant's needs. Parents are encouraged to become actively involved in their infant's care.

Parenting the Growing Preemie. 9 min. $175. After parents have adjusted to the environment of care in the NICU they need to be prepared for playing a more active role in the preparation for taking their infant home. This video gives parents an overview of preemie development and encourages them to handle and interact with their hospitalized infant, better preparing them for discharge.

The Pediatric Video Series includes the following:

Promoting the Development of Infants with Prolonged Hospitalization. 13 min. $175. A variety of ways for promoting an infant's development during a stay in the Pediatric Unit is presented— play, adjusting routines to suit the needs of the child, the use of proper positioning and handling techniques, and involving the family in day-to-day care.

Helping Families of Infants with Prolonged Hospitalization. 11 min. $175. Nursing staff plays an important role in facilitating the adjustment of a family to an infant's hospitalization. This program teaches ways in which staff can promote successful parent-infant interaction during hospitalization in the pediatric unit and nursing strategies for optimizing a family's adjustment in preparation for the infant's discharge.

Parenting the Infant with Prolonged Hospitalization. 12 min. $175. This video is intended for showing to parents whose infants will be hospitalized for a prolonged period, to help them adjust and to play a more positive role. It helps parents to cope with the stress of having an infant in the pediatric unit, explains how they can become more actively involved with their hospitalized child, and offers them advice for helping siblings, grandparents and other close relatives deal with their own feelings.

Introduction to the NICU and Caring for Your NICU Baby (1994). Produced by Kathleen McCluskey-Fawcett, Ph.D and Marion O'Brien, Ph.D. at the Kansas Early Childhood Research Institute, The University of Kansas, Lawrence and distributed by Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-10624, tel: 800/638-3775.

Introduction to the NICU. 15 min. Parent Notebook and Professional Manual included. $43. Developed to help parents cope with the stress of having a baby in the NICU, this video introduces parents to the sights and sounds of the NICU and problems common to NICU infants. Techniques and equipment used to counteract these problems are demonstrated, and the various people who staff the NICU are introduced. The importance of parents being involved in their babies care is discussed, and basic techniques for safely touching, holding and repositioning their baby are described. Techniques for obtaining information to support caregiving is offered.

Caring for Your NICU Baby. 17 min. Parent Notebook and Professional Manual included. $49. When parents are familiar with the NICU they can begin to master skills essential to nurturing their baby. Techniques for feeding, bathing and taking a baby's temperature are demonstrated. Differences in development between pre-term and full-term babies are described, and cues that may signal illness are identified. The tape informs parents and gives them the opportunity to witness basic care techniques that can prepare them to care for their infant at home.

High-Risk Babies (1992). Produced by Dartmouth-Hitchcock Medical Center and distributed by Films for the Humanities & Sciences, PO Box 2053, Princeton, NJ 08543-2053, tel: 800/257-5126. 30 min. $149.

This program examines the causes of babies born at risk—those born prematurely and those who have other medical problems requiring a stay in the NICU. The tape looks at ways that premature delivery can be prevented, though a large percentage of such births is unexplained. The program also follows several families through the ordeal of premature delivery and the journey to home.

Preemies: The Untold Tragedy (1993). Produced by Christopher School and distributed by Films for the Humanities & Sciences, PO Box 2053, Princeton, NJ 08543-2053, tel:800/257-5126. 53 min. $149.

This documentary follows the story of babies who survived premature birth, making the case that outcomes for "miracle babies" are seldom miraculous. Many of the medicines and techniques used in neonatal units are still classified as experimental, though parents typically do not know that. Many survivors suffer lifelong health problems and can grow up with severe disabling conditions. The tape calls for long-term follow-up of survivors and for emphasis on preventative medicine.

Conference call

September, 1995

September 14-18: The Society for Behavioral Pediatrics will hold its 13th annual meeting and CME workshops September 14-18 in Philadelphia, PA. Kathryn E. Barnard and James Perrin will present a half-day workshop on ZERO TO THREE's Diagnostic Classification: 0-3 and DSM-Primary Care on Saturday, September 16. Contact Noreen M. Spota, SBP Administrative Director, 19 Station Lane, Philadelphia, PA 19118-2939, tel: (215) 248-9168.

September 20-22: The California Department of Developmental Services will sponsor a Governor's Conference, Partners in Prevention III, in San Diego, California. Jack P. Shonkoff will give a special address, "Promoting Child Competence: The Science of Early Intervention Programs." Contact the Department of Developmental Services, 1600 9th Street, Sacramento, CA, tel: (916) 654-2773.

September 20-22: The National Association of Children's Hospitals and Related Institutions will hold its annual meeting in Milwaukee, Wisconsin, with the theme "Value vs. Values, Mission vs. Margin." Speakers will include Laurence O'Connell, Irwin Rubin, and Amitai Etzioni. Call Helen McBride, NACHRI director of education, at (703) 684-1355.

September 28-30: The National Black Child Development Institute will hold its Twenty-fifth Anniversary Annual Conference, "Renewing the Spirit of Excellence," in Washington, D.C. Contact Vicki Pinkston, NBCDI, 1023 15th Street, N.W., Suite 600, Washington, D.C., 20005, tel: (202) 387-1281 or 1-800-556-2234.

September 28-October 1: The Association for Pre- and Perinatal Psychology and Health will hold its 7th International Congress in San Francisco, California on the theme, "Birth and Violence: The Societal Impact." Speakers will include, among others, Marshall Klaus, Lloyd deMause, and Michael Trout. Contact APPAH, 599 Stevenson Avenue, Alexandria, VA 22304-3300.

October, 1995

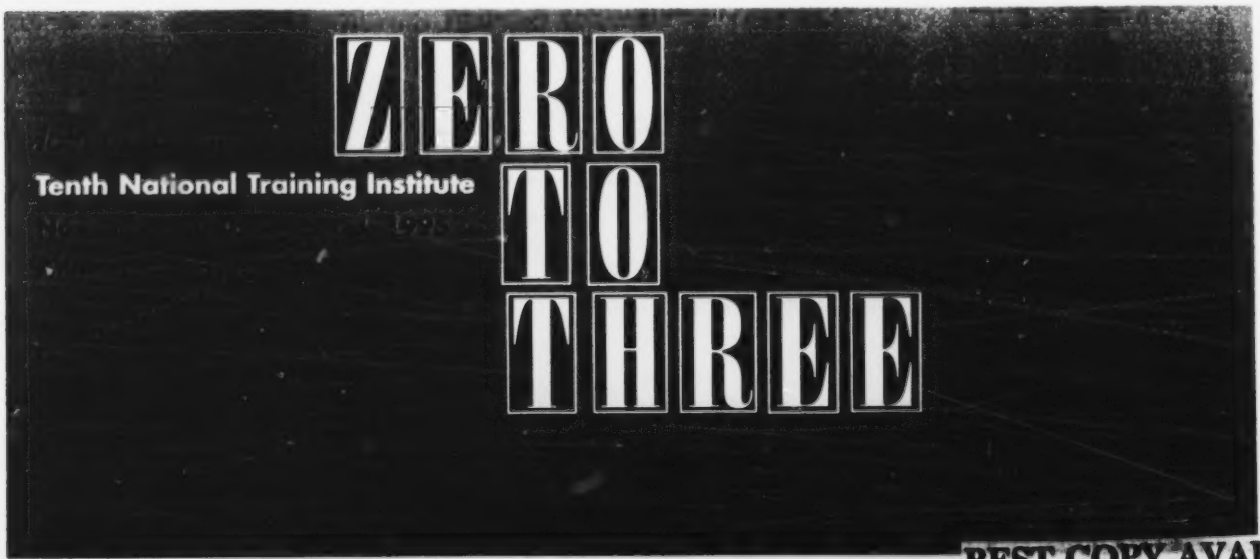
October 13-15: Healthy Mothers, Healthy Babies Coalition will hold its biennial educational conference in Rosslyn, Virginia (outside Washington, DC) on the theme, "Promoting Prenatal Care: Strengthening Linkages and Empowering Communities." A national forum for community perinatal outreach workers will be held October 11-12. Contact HMHB, 409 12th Street, S.W., Washington, D.C. 20024, tel: (202) 863-2552; fax: (202) 484-5107.

October 20: The California Infant Development Institute will sponsor a one-day seminar in Los Angeles by Stanley Turecki, who will discuss "Temperament Issues in Toddlers and Preschoolers." Call (213) 851-6122.

November, 1995

November 1-5: The Division for Early Childhood of the Council for Exceptional Children will hold its 11th annual international conference on children with special needs in Orlando, Florida, with the theme, "Broadening Realities: Valuing Diversity." Valora Washington and Beth Harry will deliver plenary addresses. For information, write to DEC Conference, 3 Church Circle, Suite 194, Annapolis, MD 21401.

November 17-19: The National Perinatal Association will hold its annual clinical conference and exposition in Washington, D.C. Contact Contemporary Forums Conference Management at (510) 828-7100, x0, or NPA at (813) 971-1008.



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Back issues of *Zero to Three* are available for $6 each from
ZERO TO THREE, 2000 14th Street North, Suite 380, Arlington, VA 22201-2500 or by calling 1-800-899-4301.
Shipping and handling charges are:
$2.50 for orders under $10,
$4.00 for orders $10-59.
Zero to Three reserves the right to supply photocopies of issues no longer in print. Topical indexes of Volumes 1-14 (September, 1980 - June/July, 1994) are available on request.

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